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Promoting Social Inclusion for Persons with Intellectual Disability
and other Neurological or Developmental Disorders in Albania

Social Inclusion

Jon Lazri, Natalie Milgram, Andrew Nolan, Julisse Sabater



WPI



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**Promoting Social Inclusion for Persons with Intellectual Disability and
other Neurological or Developmental Disorders in Albania**

An Interactive Qualifying Project Report Submitted to the Faculty of the
WORCESTER POLYTECHNIC INSTITUTE
in partial fulfillment of the requirements for the Bachelor's Degree

By: Jon Lazri, Natalie Milgram, Andrew Nolan, and Julisse Sabater

Date: December 11, 2019

Advisors: Professor Robert Hersh & Professor Robert Kinicki

Report Submitted to: Leave No One Behind Program

This report represents work of WPI undergraduate students submitted to the faculty as evidence of a degree requirement. WPI routinely publishes these reports on its web site without editorial or peer review. For more information about the projects program at WPI, see <http://www.wpi.edu/Academics/Projects>.

Abstract

Working with the United Nation's Leave No One Behind Programme in Albania, this project documented and assessed the current state of social inclusion for persons with intellectual disabilities and other neurological or developmental disorders. The team conducted 31 interviews with persons with disabilities, their parents, service providers, and government officials in Tirana, Albania. The project analyzed the qualitative data gained from our conversations to uncover themes of discrimination, insufficient services, and mistreatment towards people with disabilities. From these findings, the team suggested areas of future research, information sessions, and community interventions which aim to improve the social inclusion of persons with disabilities in Tirana, Albania.

Acknowledgements

Our team would like to thank everyone who helped to make this project possible:

Everyone at the **Leave No One Behind Programme** for sponsoring this project. Specifically, **Anduena Shkurti** for taking the chance to partner with WPI on an IQP and **Andi Bregu** for guiding us and being there with us every step of the way, also getting us addicted to coffee.

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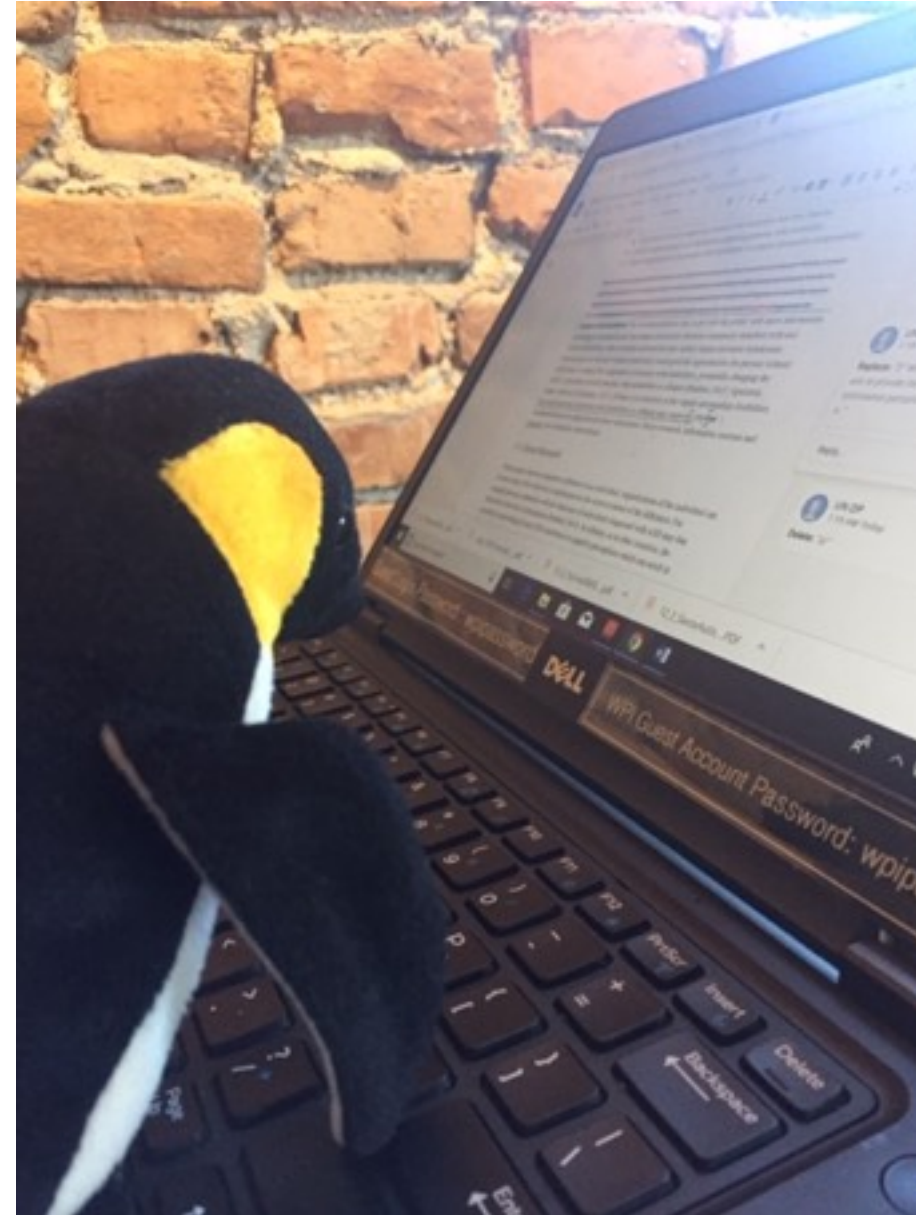


Figure A.1: Nigel Doing his Part

Executive Summary

Throughout history, persons with disabilities have faced prejudice and discrimination across the globe. The ancient Greeks viewed the “sick” as inferior and Plato advised that the “deformed offspring” be put away in some “mysterious, unknown place” (Viljoen, 1959).

Even today the stigmatization of persons with disabilities worldwide negatively affects their inclusion in communities (European Commission, 2010). In Albania, researchers in the field of disabilities and government officials in the field of social work consider persons with disabilities to be one of the most discriminated against populations (Kulla, 2015; B. Kosperi, personal communication, November 7, 2019). By reducing misconceptions and stigma surrounding persons with disabilities, inclusion can be improved (European Commission, 2010).

Our sponsor for this project is The Leave No One Behind Programme (LNB), a United Nations program run by the UNDP. LNB promotes social inclusion for all vulnerable persons in Albania (UNDP, n.d.). The goal of

our project was to document and assess the current state of social inclusion of persons with intellectual disabilities, developmental disabilities, and other neurological disorders in Tirana from the perspectives of persons with disabilities, their family members, social service providers, and Albanian government officials in the field of social services. Our assessment of social inclusion for these populations guided us to suggest recommendations which aim to promote the social inclusion of persons with disabilities in Albania.

Background

Many factors impact social inclusion for persons with disabilities. Dr. Sarah Hall (2010), a researcher in the field of educational studies at the University of Minnesota, argues that persons with ID who experience social inclusion within society must have full access to activities within the community and opportunities for satisfying and reciprocal relationships. In addition to the physical accessibility of public community spaces, social inclusion involves the psychological feelings of satisfaction and

belonging towards a person’s surrounding community (Hall, 2010). One factor that hinders social inclusion is stigma. Haddad (2015) defines stigma with three components: ignorance, prejudice, and discrimination.

Approach

We assessed and documented the current state of social inclusion from the perspectives of young adults with disabilities, parents of children with disabilities, disability service providers, and government officials involved with social services to work towards our project goal.



Figure E.1: The Team Interviews a Young Adult and Parent

Our sample included persons with ID, ASD or other developmental disorders who were aged between 16 and 37 years old. The team scheduled interviews with the help of LNB and then conducted interviews with 31 people over the course of three weeks. The team prioritized interviews with persons with disabilities to encourage their self-advocacy. We used an unstructured approach during interviews, engaging in freeform conversation with the help of a translator. During interviews, we covered topics which included friendships, discrimination, plans for the future, and persons with disabilities' community involvement. Our qualitative data was comprised of interview notes, audio recordings, and interview transcripts.



Figure E.2: The Team Works on Data Analysis

Findings

After analyzing our data from interviews, the team identified three major findings.

1) Negative School Experiences

Persons with disabilities in our sample spoke of their negative experiences in the public school system. Five out of seven parents of persons with disabilities interviewed claimed that teachers were not properly trained to work with their children. One parent stated “School life was terrible for my son....they were not qualified to provide services for him.” One young adult with ASD told us that the years of junior high school were “the worst years of my life as I can remember.”

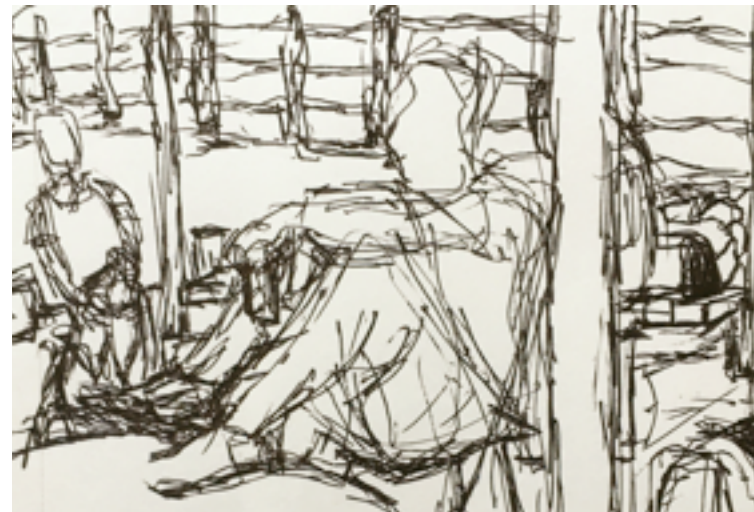


Figure E.3: Sketch 1 by Natalie Milgram

2) Stigma and Mistreatment

All stakeholders noted the evident stigma and discrimination towards persons with disabilities in Albania. Eight out of 14 of the young adults with disabilities interviewed said they experienced some sort of mistreatment. One young adult stated “they [peers] tease me they tease me... they do not want to play with me.” Eleven out of 14 young adults interviewed said they felt isolated and did not have friends outside of their respective service centers. However, all young adults in our sample currently receiving services expressed satisfaction regarding their social inclusion within their service centers.

3) Services are Insufficient and Inaccessible

The team found that parents provide immense support for their children with disabilities. All parents interviewed expressed dissatisfaction with the current social service system. One parent was unable to transport her son to a service provider due to the long-distance commute, stating “They build centers where no one can go.” Another parent became emotional during an interview, stating “They [public service centers] do not offer the correct process of therapy. When my son begins to cry, they send him out.” Service providers voiced their

dissatisfaction towards the Albanian government's efforts in supporting persons with disabilities.

Recommendations

From our research findings and observations, we proposed three sets of recommendations:

1. Future Research

Future research can help to educate society which may reduce stigma and improve social inclusion for persons with disabilities in Albania. Our specific recommendations for future research topics include:

Autism Spectrum Disorder (ASD)

Our findings and personal observations suggest that persons in Albania lack information on ASD. Additionally, documentation on teachers' current understanding of ASD would help the Ministry of Education develop more effective trainings for educators.

Specific Demographics Regarding Persons with Disabilities in Albania

Information regarding specific demographics of persons with disabilities in Albania is limited. More updated disability demographics would help the government

determine optimal locations and services of future service providers.

2. Information Sessions and Trainings

While future research can educate the public on disabilities, formal trainings would more effectively provide teachers and parents with information relevant to their specific needs. We recommend information sessions for two groups:

Information Sessions for Parents

Parents interviewed sometimes had misconceptions regarding their child's disability. We recommend that LNB or service providers hold information sessions to educate the parents of persons with disabilities on their child's diagnosis. These information sessions should explain the limitations associated with different disabilities.



Figure E.4: Leave No One Behind Logo (al.undp.org)

Trainings for Educators on Inclusive Education for Persons with Disabilities

We recommend that the Ministry of Education facilitates additional trainings in public schools to educate teachers on working with students with disabilities. These trainings should explain the best practices for managing challenging behavior of special needs students. Additionally, trainings should discuss techniques for educating and communicating with students with ASD, ID, and other developmental disabilities. We recommend that these trainings encourage teachers to welcome students with disabilities into their classrooms.



Figure E.5: Albanian Ministry of Education Logo (acce.al)

3. Community Intervention Recommendations

The following recommendations encourage interactions between persons with and without disabilities and aim to increase

persons with disabilities' community involvement.

Organize Friendships Between Students with and without Disabilities in Mainstream School Settings (the “Best Buddies” program)



Figure E.6: Best Buddies Program Logo (<https://www.bestbuddies.org/>)

A program of arranged friendships, similar to the Best Buddies program in the United States, could help promote integration and encourage friendships between persons with and without disabilities in the public school setting. This program matches students with disabilities to a peer without disabilities in a

“Buddy Pair.” These pairs of students participate in weekly activities during free time or after school hours.

University Students Interning at Service Providers

Service providers often struggle to maintain sufficient staffing. We recommend that university students studying education or social services intern at service centers. This recommendation would benefit both university students and service providers. Students would gain hands on experience and service providers would have more support staff. Furthermore, sufficiently staffed service providers would run more efficiently, potentially improving the social inclusion of persons with disabilities within service centers.

Skills Trainings for Young Adults with Disabilities at University Campuses Taught by Students

Our team recommends that university students lead vocational trainings on college campuses for adolescents and young adults with disabilities. Persons with disabilities could learn valuable skills and form satisfying social relationships with peers who do not have disabilities. University students would gain hands on experience working with persons with disabilities. An experienced

university professor in the field of psychology, social services, or education would oversee these trainings to ensure college students appropriately interact with persons with disabilities.

Conclusion

Discrimination against persons with disabilities persists within Albania and stigma continues to surround disabilities worldwide. We have been honored to assist LNB with their efforts to improve the social inclusion of persons with IDs, developmental disabilities, and ASD in Albania. Humans are animals who have biological instincts of fear towards the unknown (Garpenstrand, Annas, Ekblom, Orelund, & Fredrikson, 2001). While uncertainty and lack of information can lead to stigma and discrimination against persons with disabilities, human behavior can change with time and effort. We hope this research serves as a steppingstone to reduce the stigma surrounding disabilities over time.

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Authorship

Our whole contributed to the creation of this report. Before writing any chapters the group met to brainstorm and outline the content of the section. Each section has gone through many rewrites (nine versions of the intro, eight versions of the background, 12 versions of the approach, five versions of findings, and three versions of the conclusion). The authors who wrote the current versions of the sections do not represent the effort put in by team members in contributing to these sections throughout the term, so we wish to describe our writing process rather than disproportionately represent the authorship of each section. Natalie and Andrew often took the role of lead writers. Everyone contributed to editing, with Natalie often being the lead editor. Julisse served the role of lead graphic designer. Jon's interpersonal skills and Albanian helped him lead interviews and help us navigate working in Albania. All members used their skills to equitably contribute to the project.



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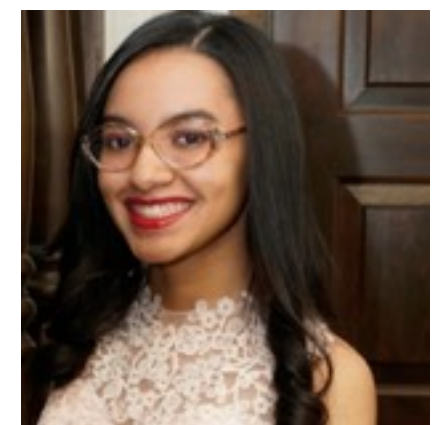


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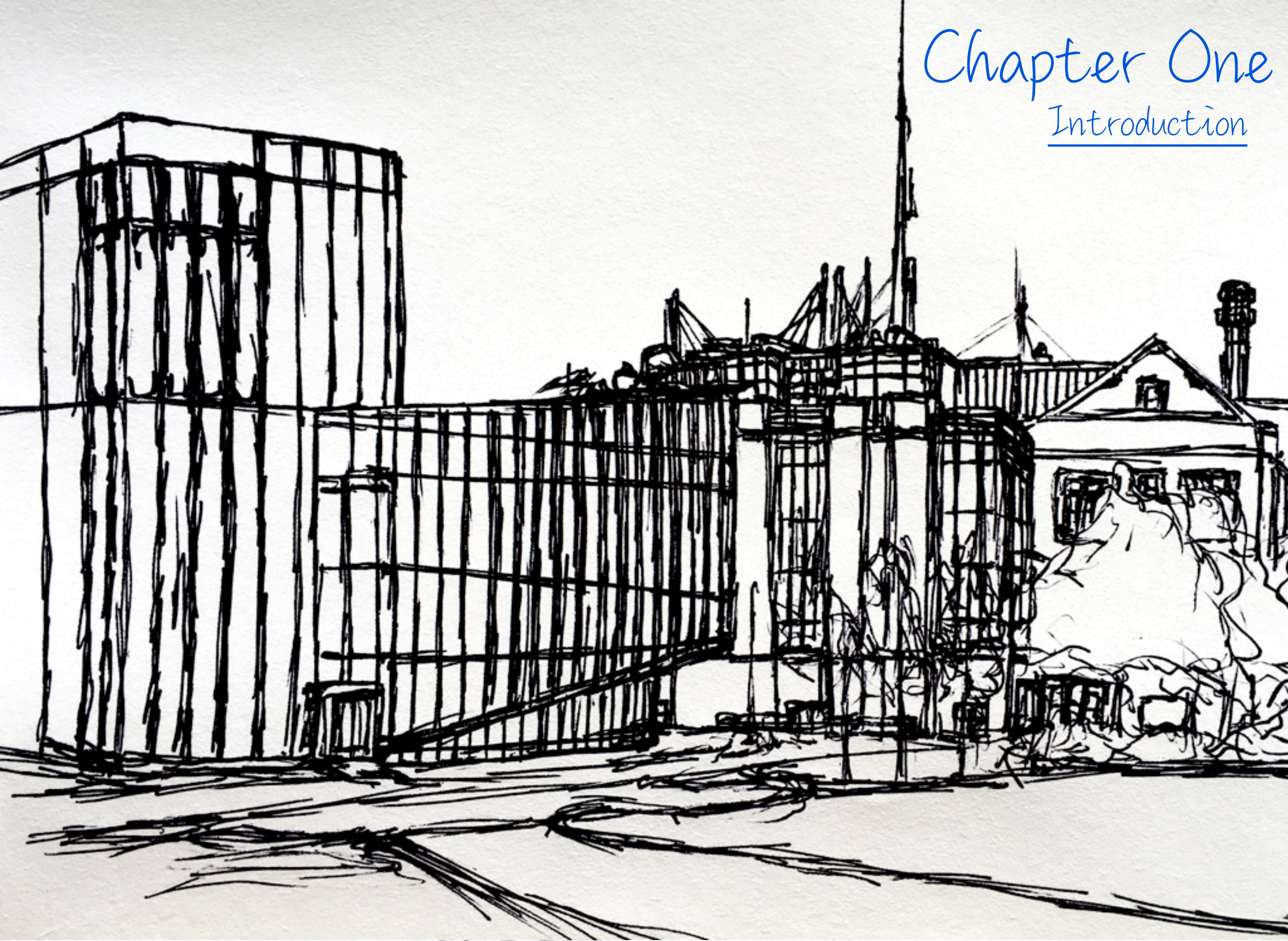
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Chapter One

Introduction



Introduction

Throughout history, persons with disabilities have faced prejudice and discrimination. In ancient Greece, the “sick” were considered inferior and Plato advised that the “deformed offspring” be put away in some “mysterious, unknown place” (Viljoen, 1959). In 16th century Europe, some religious leaders believed people with disabilities were possessed by evil spirits. They subjected persons with disabilities to physical and mental pain in an effort to “purify” them and exorcise the supposed spirits (Munyi, 2012). In 1883, Sir Francis Galton introduced the term “eugenics” and described it as an effort to improve the human race. This ideology spread throughout the United States in the 1900s and resulted in several state laws which allowed “undesirables” including persons with disabilities to be involuntarily sterilized (Grenon & Merrick, 2014). In the 1960s, societies continued to isolate persons with disabilities. One institution in Melbourne, Australia warehoused children with profound intellectual disability in large wards where they lived malnourished and under-stimulated, unable to communicate the inhumane conditions they suffered (Drake & Kliever, 1998).

Even in the 21st century, society still stigmatizes disabilities, sometimes by the organizations and institutions claiming to support persons with disabilities. One autism advocacy organization, Autism Speaks,

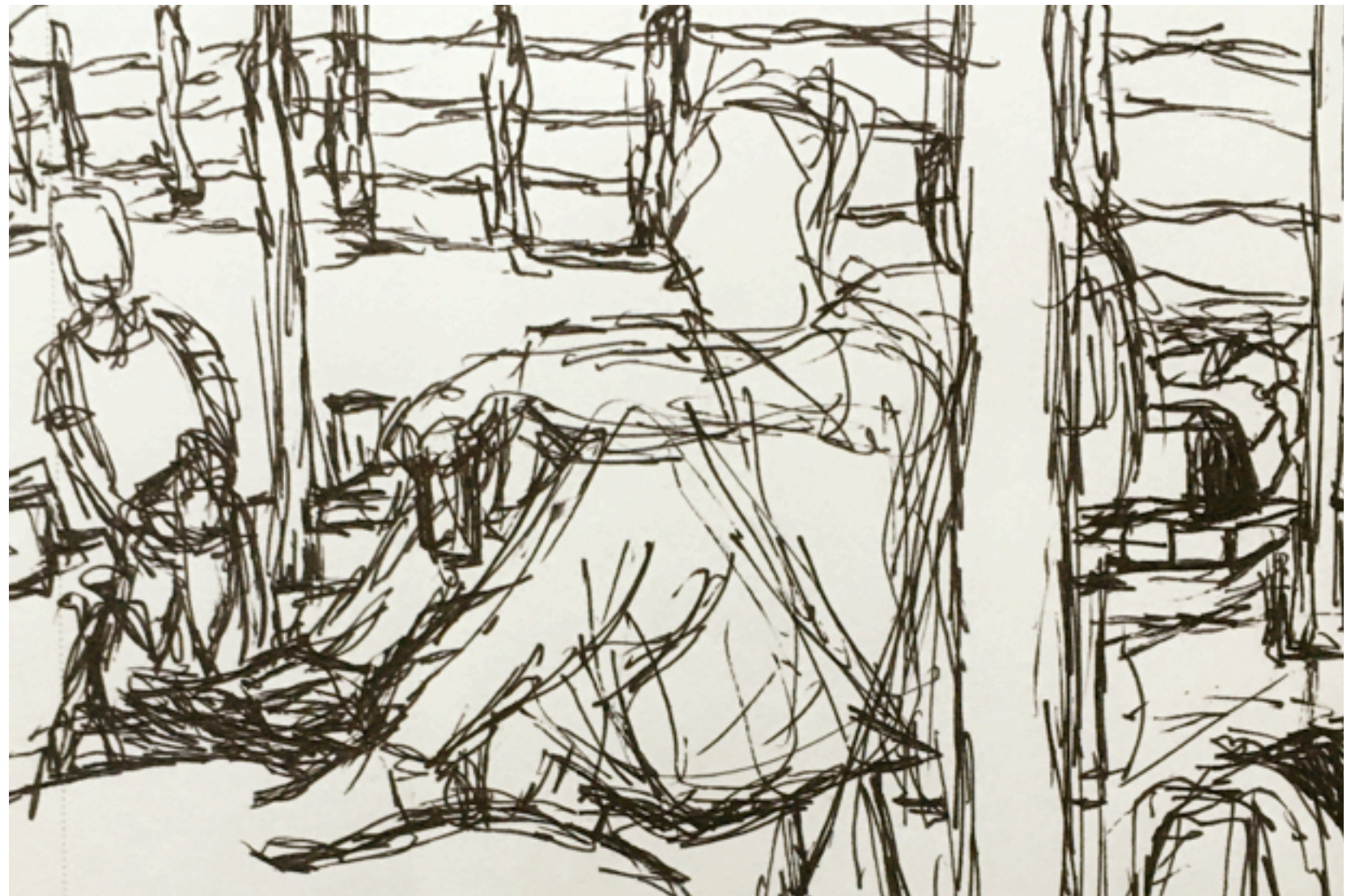


Figure 1.1: Sketch 2 by Natalie Milgram

released a controversial short film “I Am Autism” in 2009 which negatively described autism as something that will make sure “your marriage fails” and “rob you of your children” (Autism Speaks, 2009). Ari Ne’eman, co-founder of the Autistic Self-Advocacy Network, claimed that this video portrayed autistic people as “burdens or objects of fear and pity” (Wallis, 2009). Today, persons with disabilities still face inhumane treatment in the United States.

The Judge Rotenberg Educational Center in Canton, MA continues to administer inhumane electric shock “treatments” to people with developmental disabilities. The FDA is currently trying to ban the skin shock therapy device and Laurie Ahern, president of the Washington, D.C.-based nonprofit Disability Rights International, argues the treatment is “sadistic” and describes it as “torture” (Mckim, 2019).

Even today, the stigmatization of persons with disabilities worldwide negatively affects their inclusion in communities (European Commission, 2010). In Albania, researchers in the field of disabilities and government officials in the field of social work consider persons with disabilities to be one of the most discriminated against populations (Kulla, 2015; B. Kosperi, personal communication, November 7, 2019). Communities may improve inclusion by reducing misconceptions and stigma surrounding persons with disabilities (European Commission, 2010). Social inclusion for persons with disabilities includes equal access to community spaces and reciprocal social relationships which allow people to feel they belong in society (Hall, 2010).

In Albania, few community services are available to provide support to persons with intellectual disabilities over the age of 21. Recent passage by the Albanian parliament of the Law on the Inclusion of and Accessibility for Persons with Disabilities provides a strong legal framework which supports the rights of persons with disabilities. However, municipalities lack funding from the central government to implement community programs (A. Shkurti, personal communication, September 12, 2019). Albanian service providers may lack funding, social capital, or well-trained staff which can make it challenging for them to offer services (Felix, 2013). Our sponsor for this project is The Leave No One Behind Programme (LNB), a United Nations program in Albania funded by the Swiss government. LNB acknowledges the lack of community resources and works to support municipalities in providing social services as part of its main goal: social inclusion of all vulnerable persons in Albania. This program began in June of 2017 and will remain in effect until May of 2021 (UNDP, n.d.).

The goal of our project was to recommend community interventions which aim to improve social inclusion for persons with intellectual

disability (ID) and other neurological and developmental disorders in Albania. We documented and assessed the current state of social inclusion of persons with disabilities in Tirana from the perspectives of persons with disabilities, parents of children with disabilities, disability service providers, and government officials involved with social services to work towards this goal. The team conducted 31 interviews in total with all of these stakeholders. This project aims to assist LNB with its objective of including all vulnerable groups in Albania.

Through field work, the team identified prominent themes of discrimination, misconceptions about disabilities, and a lack of available support. With this research, the team documented the experiences of persons with disabilities from their perspective. We proposed community interventions and suggested areas for future research which aim to improve social inclusion for persons with disabilities in Albania.



Figure 1.2: Sketch 3 by Natalie Milgram

Chapter Two

Background



Background

2.1 Intellectual Disability, Down Syndrome, and Autism Spectrum Disorder

Guidelines for Diagnosing Medical Conditions Around the World

Healthcare professionals around the world use different sets of guidelines to diagnose persons with both physical and mental disabilities. In the United States, professionals use the Diagnostic Statistical Manual of Mental Disorders (DSM) to diagnose persons with mental illnesses or other non-physical disabilities described as mental disorders. This manual includes specific sets of diagnostic criteria associated with a number of mental disorders recognized by healthcare professionals (APA, 2009). While American professionals typically use the DSM to diagnose disorders in the United States, the World Health Organization (WHO) manages and publishes the International Statistical Classification of Diseases and Related Health Problems (ICD). Healthcare professionals across 117 countries use the ICD to diagnose persons with both mental disorders and physical conditions. Both the DSM and ICD have gone through multiple iterations as professionals have updated diagnostic criteria for conditions, added new disabilities,

and changed the classifications of various disorders (APA, 2009).

Intellectual Disability

Both the DSM and ICD contain definitions of intellectual disabilities which involve impairments in cognitive skills (APA, 2009;

World Health Organization, 2016). In the ICD-10, the most current version of the ICD classification system, an intellectual disability is called “mental retardation” and is defined as “a condition of arrested or incomplete development of the mind” which results in impairment of cognitive skills (World Health



Figure 2.1: A Stethoscope (https://cdn.pixabay.com/photo/2019/06/18/01/06/ecg-4281207_1280.jpg)

Organization, 2016). While the ICD titles this condition “mental retardation,” the World Psychiatry Association (2011) claims this wording is offensive and instead proposes the term “intellectual disability” (ID) be used internationally (World Psychiatry Association, 2011). For our report we use the term intellectual disability.

IDs range from mild to profound, resulting in impairments which can affect daily functions in varying ways. Persons with ID may find it difficult to communicate with other people, learn new skills, or maintain personal hygiene (DSM-5, 2013). The impairments from ID can make it hard for people to secure employment, live an independent life, and develop relationships. They can also limit persons with ID’s participation in the community and interfere with their social relationships which may lead to social exclusion (World Health Organization, 2011).

Approximately 200 million people worldwide live with an intellectual disability (CDC, 2019; Special Olympics, n.d.). According to one Albanian disability expert, approximately 40-50% of persons with disabilities in Albania have some form of intellectual disability (F. Kalemi, personal communication, November 5, 2019).

Down Syndrome

While the ICD provides a somewhat thorough definition of intellectual disabilities, they do not define Down syndrome with as much detail. The ICD classifies Down syndrome as a chromosomal abnormality (World Health Organization, 2016). Down syndrome is a congenital condition characterized by developmental delays, impairments in cognitive functioning, and abnormalities in physical features (Merriam Webster, 2019).

Autism Spectrum Disorder

Both the DSM and ICD define autism as a condition resulting in difficulties with social communication and repetitive behaviors or interests (APA, 2009; World Health Organization, 2016). IDEA (2004) classifies autism as a developmental disability (Individuals with Disabilities Education Act, 2004). The latest version of the DSM defines autism as a spectrum disorder titled Autism Spectrum Disorder (ASD). Neither the DSM or ICD include any mention of cognitive impairments in their diagnostic criteria of ASD or any disorders falling within the autism spectrum (APA, 2009; World Health Organization, 2016). Less than one in five people diagnosed with ASD receive an intellectual disability diagnosis (Edelson, 2006).

While the DSM and ICD clearly separate ASD from ID, misinformation spread through the Internet, word of mouth, and advocacy groups can result in a misconception that all persons with ASD also have an intellectual disability (APA, 2009; World Health Organization, 2016; Savoy, 2014).

The American Center for Disease Control states that 1 in 59 people have ASD. No reliable data pertaining to the precise number of people diagnosed with ASD exists within Albania. Difficulties in diagnosing persons with ASD or limited research pertaining to ASD within Albania may cause this lack of information (Kulla, 2015).

2.2 Social Inclusion for Persons with Disabilities

The concept of the social inclusion for persons with disabilities has many aspects. Dr. Sarah Hall (2010), a researcher in the field of educational studies at the University of Minnesota, argues in her PhD thesis that persons with ID who are socially included within society must have full access to activities within the community and opportunities for satisfying and reciprocal relationships. In addition to the physical accessibility of public community spaces, social inclusion involves the psychological feelings of satisfaction and belonging to a

person's surrounding community (Hall, 2010).

Social Inclusion and Satisfying Relationships

As Hall (2010) notes, social inclusion for persons with ID involves satisfying relationships and meaningful interactions with friends, family, and community members (Hall, 2010). The Massachusetts Department of Developmental Services (2015) claims that persons with ID who have satisfying friendships have better physical and mental health and experience greater connections to their community (Massachusetts Department of Developmental Services, 2015). Rossetti (2015) conducted a study which analyzed friendships between high schoolers with and without disabilities in a mainstream school setting. He found that these friendships satisfied both students with and without disabilities and identified several characteristics displayed by the friendships in his sample. He highlighted that these friendships did not appear “forced, awkward, or artificial” and suggested that reciprocal relationships in which both students perceive benefits lead to satisfying friendships. Several students without disabilities in Rossetti’s study acknowledged they had more difficulty maintaining friendships with students with disabilities due to communication challenges (Rossetti, 2015).



Figure 2.2: Sketch 4 by Natalie Milgram

Several researchers have noted the challenges persons with disabilities face in forming friendships with people without disabilities, both inside and outside of school settings. Locke (2010) found that high schoolers with ASD had lower quality friendships and experienced higher rates of loneliness than their peers without disabilities (Locke, 2010). Like Locke, Moore-Dean (2016) notes that persons with disabilities have difficulties forming friendships. She suggests three important factors which help

people develop meaningful relationships, the most important being similarity or shared traits between the individuals in the friendship (Moore-Dean, 2016).

Salmon (2012) supports Moore-Dean’s claim with her finding that teenagers with disabilities felt more satisfied and included by peers who also have disabilities (Salmon, 2012). Persons with disabilities sometimes struggle to form satisfying friendships. However, meaningful reciprocal relationships



Figure 2.3: People Shaking Hands (https://live.staticflickr.com/4585/38826275042_abcea30792_b.jpg)

significantly impact the social inclusion of persons with disabilities in their communities (Rossetti, 2015; Hall, 2010).

Social Inclusion and Employment

Employment opportunities are a significant factor to facilitate social inclusion within Albanian society. In order to access and contribute meaningfully to the community persons with disabilities require some degree of independence. Employment allows persons with disabilities to become

financially independent and gain additional resources to enhance their inclusion (A. Bicaku, personal communication, November 8, 2019). Persons with disabilities in Albania face difficulties in gaining employment, especially those with intellectual disabilities (Kalemi, personal communication, November 5, 2019). There is a lack of vocational training and inadequate inclusive education training for teachers. These factors contribute to the low rates of employment for persons with ID. The low employment rates can result in the misconception that persons with ID are not

involved in society, which negates the potential for their social inclusion (A. Seiti, personal communication, November 4, 2019). In Albania, the government has passed legislation to promote the employment of persons with disabilities. The law on employment states that employers must recruit one person with a disability for every 25 employees without any diagnosed disabilities. However, some employers would rather pay a fine than hire someone with disabilities (FIMITIC, 2011).

2.3 Stigma and Discrimination Against Persons with Disabilities

Discrimination Against Persons with Disabilities

Mistreatment of persons with disabilities persists and persons with intellectual disability continue to face discrimination. Researchers in the United Kingdom analyzed data from two UK surveys which asked participants with and without intellectual disabilities to self-rate their health and discrimination/violence faced in everyday life. Roughly 36% of participants with intellectual disabilities responded that they had been treated unfairly within the past 12 months compared to only 12% of participants without ID. In addition, participants with ID reported that they had experienced more violence and were victims



Figure 2.4: Sketch 5 By Natalie Milgram

of hate crimes more often than those without ID in the past 12 months (Emerson et al., 2014).

Several Albanian disability experts suggest persons with intellectual disabilities comprise one of the most discriminated groups in Albania (A. Seiti, personal communication,

November 4, 2019; F. Kalemi, personal communication, November 5, 2019).

One researcher, Kulla (2015), notes that discrimination persists against persons with ASD. He found that children with ASD form one of the most stigmatized groups in Albania, further claiming that they

face “continuous verbal abuse” in the school setting (Kulla, 2015).

Stigma, Prejudice, and Discrimination

Madi (2019) characterizes stigma as negative perceptions and limited acceptance by community members. Stigma becomes evident when community members without disabilities behave in ways which make persons with disabilities feel uncomfortable (Madi, 2019). Haddad (2015) defines stigma as having three components: ignorance, prejudice, and discrimination. He describes prejudice as a negative attitude which results in discrimination, the actions which disadvantage the stigmatized people in question. Haddad and other researchers have argued that ignorance, or lack of information, results in prejudice, or negative perceptions, of persons displaying some difference in physical appearance or mental functioning (Haddad, 2015; Arboleda-Florez, 2002). In contrast, other professionals separate stigma and discrimination, defining stigma as a negative view due to an observed difference perceived as detrimental. The Mayo Clinic claims that stigma can, but does not necessarily, lead to discrimination or actions towards the stigmatized which disadvantage the persons with marked differences (Mayo Clinic, 2015).

For our report, we define discrimination as evidence of stigma.

Discrimination and Implicit Bias

Bortolotti (2019) suggests that discrimination is not always intentional, claiming humans can display implicit bias, or unintentional prejudices and behaviors difficult or impossible for them to control (Bortolotti, 2019). Lack of information, or ignorance, can

result in discrimination, however humans can exhibit involuntary discriminatory behaviors caused by the biological makeup of the human brain. Survival instincts which keep the human race alive, may contribute to involuntary negative perceptions of persons displaying visible differences. This implicit bias can be reduced if humans gain exposure to the stigmatized people seen as different or atypical (Bortolotti, 2019; Brownstein, 2019).

Stigma and Discrimination in the School Setting

Many researchers in the field of education have observed and studied the cause and effect of ignorance and stigma described by Haddad. Siperstein, Parker, Bardon, and Widaman (2007) analyzed survey responses from 5,837 middle school students in the United States. These researchers concluded within a 1.4% margin of error that students with ID experience discrimination from their peers in school. Siperstein argued the discrimination resulted from the middle schoolers' inaccurate perceptions of their peers with intellectual disabilities. The researchers argued that students without disabilities need both "contact and exposure" to students with disabilities and further suggested that the exposure will allow students without disabilities to witness the competence of students with disabilities.



Figure 2.6: Two Students Working (live.staticflickr.com)

This contact and exposure can result in a change of perception which could reduce stigma surrounding intellectual disabilities over time (Siperstein, Parker, Bardon, & Widaman, 2007).

Cooney (2006) conducted a different study in the UK which found that students with intellectual disabilities experienced discrimination in both mainstream and special education schools. He concluded students with IDs in mainstream schools experience significantly more discrimination than students with IDs in segregated schools (Cooney, 2006). Ditchman (2013) argues that social inclusion of persons with intellectual disabilities in mainstream school settings leads to more stigma initially. She cites Siperstein and agrees that inclusive education for persons with IDs can reduce stigma over time, but argues that the initial



Figure 2.5: Sketch 6 By Natalie Milgram

forced interactions between students with and without disabilities results in temporary fear and discomfort (Ditchman, 2013). Siperstein's study affirms Haddad's argument that ignorance results in discrimination and further supports the claim that forced exposure results in less ignorance, less stigma and therefore less discrimination (Siperstein, Parker, Bardon, & Widaman, 2007; Haddad, 2015).

2.4 Inclusive Education for Persons with Disabilities in Albania

Albania has recently begun a push to promote inclusive education for persons with disabilities. The Albanian government currently prioritizes accessibility of education for persons with disabilities to promote their social inclusion within society. However, stigma and discrimination remain prevalent within the school setting (B. Kospiri, personal communication, November 7, 2019). In an Albanian study on inclusive education for children with ASD, Kulla (2015) found that teachers lack knowledge pertaining to educating students with ASD. He discovered teachers have difficulties handling challenging behaviors of students with ASD and found that school staff can feel incapable of working with these students one on one. In Albanian public schools, teachers who are not specialized in special education

create Individual Education Plans for students with ASD, however they lack the training to develop quality plans for students with disabilities. In Albanian service provider centers for autistic children, professionals evaluate the service users with ASD and develop higher quality individual care plans which include learning and development objectives. Kulla argued that the lack of training on educating students with ASD is one factor contributing to the discrimination against this population in the public-school setting. He noted that autistic children face "continuous verbal abuse" in schools and concluded "The whole experience of children with autism in mainstream schools is full of unexpected events, mainly because the schools do not have clear plans, procedures, structures and services to help the inclusion of these children" (Kulla, 2015, p. 54).

Dr. Nereida Balla (2015) conducted similar inclusive education research in Albania which yielded findings comparable to Kulla's study. He surveyed 520 people in Tirana and Durrës. His sample included 200 teachers from public schools, 200 students from public schools, 30 education administrators, 70 parents of persons with disabilities, and 20 students with disabilities. Balla found that teachers felt unprepared to work with some students with disabilities. Kulla's research found that teachers felt overwhelmed by the



Figure 2.7: Globe Image (pixabay.com)

increased workload from inclusion. However, Balla suggests that teachers and students mostly view students with disabilities in a positive way. He found that 74% of educators see the benefit to mainstreaming students with disabilities into their classrooms (Balla, 2015). Professor Rovena Lika (2016) from the European University of Tirana found that some teachers in Albania lacked education on techniques to manage the behavior of students with disabilities. Lika further emphasized teachers trained on inclusive education have a more positive mindset towards the integration of students with ID into public schools. Lika suggested that schools educate Albanian teachers on strategies to minimize the bullying of students with disabilities and introduce

teachers to individuals with ID during their training (Lika, 2016).

2.5 The Role of Parents in Raising Children with Disabilities

Many parents of persons with disabilities offer significant support to their children throughout the day. Dr. Rosaleen Rushe (2015) conducted a study in Sligo, Ireland, which examined parents' roles in raising children with intellectual disabilities. Rushe noted that parents thought caring for their child was both demanding and rewarding. Parents in Rushe's study felt stressed because caring for their child took up much of their time. Rushe concluded that parents feared for their child's safety when their child was alone. Parents in the study spent most of their time with their child because of this fear (Rushe, 2015). Sarvananthan (2017) also mentions the demands parents face in raising a child with ID. He states parents can become mentally exhausted when caring for children who have IDs and argues that caring for a child with ID is a lifelong process (Sarvananthan, 2017). A different study in Malawi conducted by Masulani-Mwale (2016) similarly found parents experience severe stress when raising their child with disabilities. He emphasized that the lack of available services in Malawi contributed to this stress (Masulani-Mwale, 2016). Gauthier-



Figure 2.8: Art Therapy Image

Boudreault (2017) found that a lack of available services and supports induced stress in parents of children with ID (Gauthier-Boudreault, 2017). Parents often act as an advocate for their child, requesting therapies and services on their child's behalf (F. Kalemi, personal communication, November 5, 2019).

While parents provide a large source of support for their children, they sometimes have misconceptions about their children with disabilities and underestimate their abilities (E. Mataj, personal communication, November 5, 2019). University of Nottingham Professors Pilnick, Clegg, Murphy, and Almack (2011) conducted a study which assessed the family dynamics during Individualized Education Program meetings at schools in the United States. In these meetings, parents often drove the discussion and interjected when their child with disabilities attempted to communicate their opinion. Pilnick found that parents sometimes spoke on behalf of their children even when their child could express themselves. However, Pilnick and his co-workers suggest that persons with IDs cannot always make legitimate decisions for themselves (Pilnick, Clegg, Murphy, & Almack, 2011). Parents of persons with disabilities may have a complex relationship with their child. They often provide immense support and act as an advocate but can still have misconceptions regarding their child's abilities.

2.6 Legislation and International Policies Assisting Persons with Disabilities

In 2006, The United Nations drafted the Convention on the Rights of Persons with Disabilities (CRPD) in an effort to document the rights of persons with disabilities internationally and reduce the evident discrimination against this population (United Nations, 2006). Many countries now base their own legislation on the UN's convention to protect the rights of their citizens with disabilities (F. Kalemi, personal communication, November 5, 2019). In recent years, Albanian government officials developed legislation to protect the rights of persons with disabilities in Albania.

Albanian Legislation Supporting Persons with Disabilities

In 2016, Albanian government officials created The National Action Plan on Persons with Disabilities (NAPPWD). NAPPWD is in line with the principles stated in the law “On the Inclusion of and Accessibility for People with Disabilities” which includes three components: personal assistants, independent decision making, and independent living for persons with disabilities. This law gives persons with disabilities the right to make decisions on

their own behalf without the assistance of a legal guardian (F. Kalemi, personal communication, November 5, 2019).

NAPPWD is comprised of policies which aim to promote the inclusion of persons with disabilities in Albania. One policy encourages the employment of persons with disabilities to promote more community involvement. Another policy outlines a goal for more accessible community spaces. Both the National Disability Council and organizations of persons with disabilities monitor the implementation of NAPPWD which will remain in effect until 2020 (National Action Plan on Persons with Disabilities, 2016).



Figure 2.9: Albanian Ministry of Health and Social Protection
(shendetesia.gov.al)

2.7 Service Providers Assisting Persons with Disabilities in Albania

Service providers assisting persons with disabilities in Albania identify as public or private depending on their funding source. Public services operate through government funding, while private services rely on contributions from external donors and payments from the parents or guardians of service users (A. Shkurti, personal communication, November 20, 2019). Public services have insufficient staffing and struggle to meet base-level needs such as suitable heating and weather protection for their building spaces. The demand for public services for persons with disabilities exceeds current capacity (M. Agalliu, personal communication, November 7, 2019).

While the existing public and private service providers offer supports to persons with disabilities in Albania, one Albanian study found that persons with disabilities are dissatisfied with current disability services in place and still feel isolated from society (Kllogjri, 2017).

2.8 Project Sponsor: Leave No One Behind Programme

Our sponsor for this project is the Leave No One Behind Programme (LNB), a subprogram of the United Nations led by the



Figure 2.10: Group Photo with Advisors and Sponsor

United Nations Development Program (UNDP) in Albania. This program began in 2017 and receives funding from the Swiss Agency for Development and Cooperation. Our sponsor works to improve the social inclusion of all vulnerable persons in Albania. Specifically, LNB aims to help groups who face severe discrimination including the Roma and disabled populations. LNB works to empower persons with disabilities by enhancing the organizational capacities of service providers at the municipality level to improve available services. Our sponsor supports national institutions in implementing social inclusion policies and promotes good social inclusion practices. LNB educated upwards of 5,500 people on available social

services and inclusive education through 230 information workshops around Albania. On a local level, LNB has trained 839 professional staff from 16 municipalities on the implementation of new social care legislation. LNB will continue to promote the social inclusion of vulnerable persons in Albania until the program's predetermined end date in December of 2021 (LNB, 2019).

The goal of our project was to document and assess the current state of social inclusion of persons with intellectual disabilities, developmental disabilities, and other neurological disorders in Tirana from the perspectives of persons with disabilities, their parents, social service providers, and

government officials in the field of social services. Previous Albanian researchers have documented the state of inclusive education in Albania; however, most studies do not include data from persons with disabilities themselves (Balla, 2015). Our sponsor values the perspectives and voices of persons with disabilities. Through this research, our sponsor hopes to gain novel insights into persons with disabilities' feelings regarding their social inclusion.

Chapter Three

Approach



Approach

The goal of our project was to document and assess the current state of social inclusion of persons with intellectual disabilities, developmental disabilities, and other neurological disorders in Tirana from the perspectives of persons with disabilities, their parents, social service providers, and government officials. Our assessment of social inclusion guided us to suggest recommendations which aim to promote the social inclusion of persons with disabilities in Albania. Originally, the team intended to focus on young adults with ID, a group of persons which face particularly high rates of discrimination in Albania (B. Kospiri, personal communication, November 7, 2019).

However, due to project limitations, we followed a convenience sampling strategy. Thus, our sample expanded over the course of the project to include persons with ID and other neurological and developmental disorders who were aged between 16 and 37 years old. An even earlier version of our project involved researching independent living, specifically for persons with ID. Consequently, parts of our interview questionnaires reflect topics more related to independent living as opposed to social inclusion. The team kept some topics related to independent living as basic questions which helped us get to know the person with disabilities.

Our social inclusion research breaks down into four topics which structured our investigation in the lives of persons with disabilities in Albania. The research topics and example questions are listed in Figure 3.1.

The team conducted interviews with 31 people over the course of three weeks. These interviewees were comprised of five key stakeholders who impact the social inclusion of persons with disabilities in Albania: persons with disabilities, parents of persons with disabilities, service providers, disability experts, and Albanian government officials in the field of social work.

1. How are persons with disabilities involved within their community?

- What community events and activities do they take part in?
- How do they navigate the community?
- How do Albanian service providers and government supports promote the inclusion of persons with disabilities in the community?

2. How do persons with disabilities interact with their peers?

- Who do they spend time with during the week?
- Do they feel respected by peers?
- How do Albanian service providers promote the interactions between persons with disabilities and their peers?

3. How do persons with disabilities interact with their families?

- What support do parents provide to their children with disabilities?
- How do parents affect the social inclusion of their child with disabilities?

4. How do persons with disabilities reflect on their lives?

- What do they value in life?
- Are they satisfied with their current social relationships and community involvement?
- What are their dreams for the future?

A full list of the detailed questions can be found in Appendix I.

Figure 3.1: Research Subquestions



Figure 3.2: Zoom H 5 Audio Recording Device (zoom-na.com)

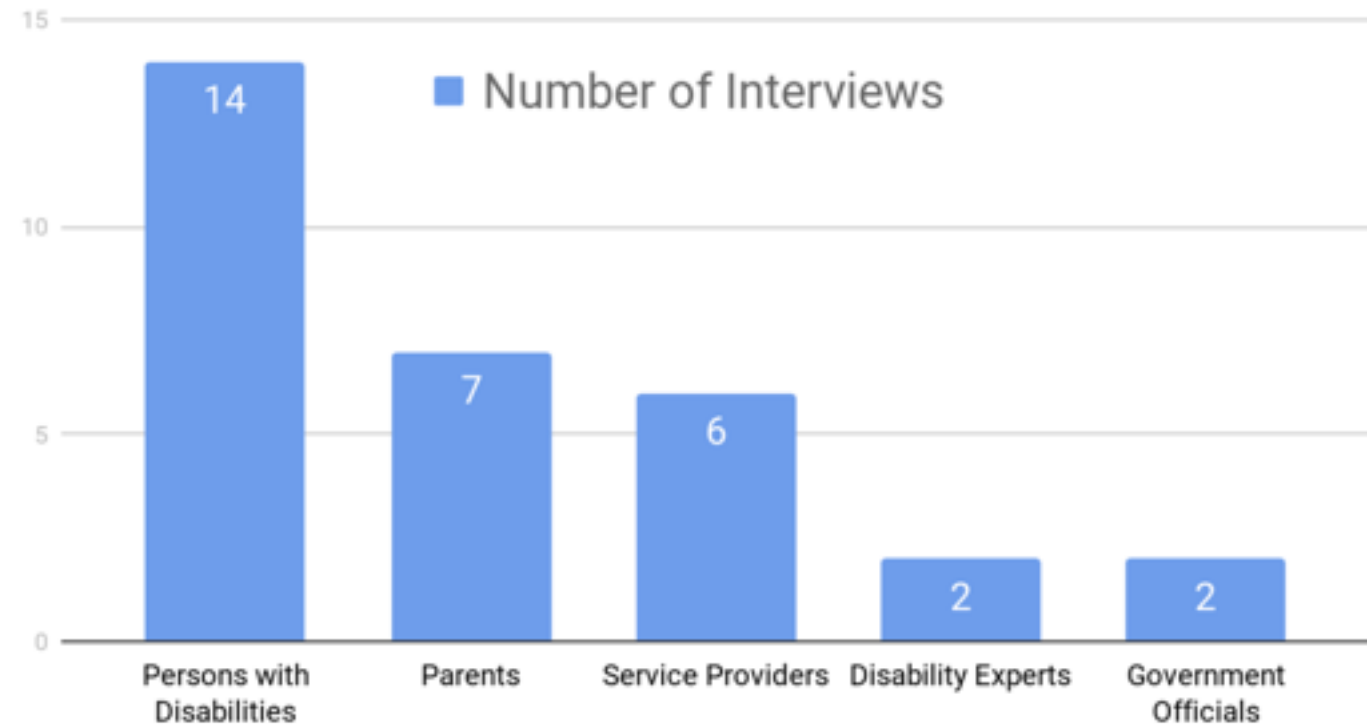


Figure 3.3: Graph of Number of Interviews Conducted

Figure 3.3 shows the breakdown of stakeholders interviewed. The team valued the opinions of all stakeholders; however, to better understand the perspectives of persons with disabilities we focused on interviewing these individuals and people who regularly interact with them such as family members and service provider staff. Interviews with government officials and disability experts helped provide context regarding the frameworks supporting persons with disabilities in Albania.

We gathered qualitative data through the course of our research which was comprised of the information and stories interviewees shared with us. This chapter describes our approach to conducting interviews and drawing conclusions from the data collected.

Section 3.1 discusses our general interview practices. Section 3.2 describes the specific measures to accommodate the communication

needs of persons with ID, Down Syndrome, and ASD. Section 3.3 explains our sampling strategy and discusses the associated limitations. Lastly, Section 3.4 concludes the chapter with a discussion of our data analysis approach.

3.1 General Interview Guidelines

Our interviews used unstructured and freeform conversations. The team prepared a semi-structured script for each stakeholder. However, as our round of interviews continued, we discovered each interviewee responded to our prepared questions differently. Three interviewees spoke for long periods of time after we

asked just one question which prevented us from asking our prepared questions. To minimize this issue, the team reformatted our initial lists of interview questions into semi-structured guidelines comprised of topics which we wanted to cover during interviews. We used these guidelines of topics as a rough checklist for the conversations which allowed us to cover desired topics through less formal follow up questions. We found that interviewees provided more valuable information when speaking freely without interruptions from team members. Figure 3.4 shows each stakeholder and the topics we wanted to cover in each interview.

Interview Topics for Each Stakeholder

Persons with Disabilities	Parents of Children with Disabilities	Service Providers	Government Officials
<ul style="list-style-type: none"> • Interviewee Activities/Interests • Personal Information • Daily Routine • Mealtimes • Family • Personal Assistant • Friends • Community • Education • Self-Reflection • Dreams for the Future • Optional Drawing/Sculpting Activity • Optional Photo-Elicitation 	<ul style="list-style-type: none"> • General Information • Daily Routine • Interactions with Peers • Community Involvement • Child's Education • Relationship with Child • Child's Desires and Feelings • Parent's Desires for their Child • Support for their Child • Programs/Services 	<ul style="list-style-type: none"> • Tell Us About Your Organization • Tell Us About Your Services • How Does Your Organization Promote Social Inclusion? • Tell Us About Your Opinions on Young Adults with Intellectual Disabilities • Tell Us About the Role of Family Members in your Services • Role of Government • Follow-up to Interview Users of the Service? 	<ul style="list-style-type: none"> • Interviewee's Role in the Government • Policies for Persons with ID • Role of NGOs/Service Providers • Role of Families • Role of Schools • Plans for the Future • Discrimination

Figure 3.4: Interview Topics for Each Stakeholder

The full semi-structured scripts for interviews with each stakeholder type can be found in appendices E, F, G, and H. The left column in the appendix tables shows a general topic the unstructured interviews sought to cover. The column on the right lists optional questions which the lead interviewer asked if the interviewee did not freely share information related to the general topic.



Figure 3.5: The Team Interviews a Young Adult and Parent

Interviews ranged in duration from 15 minutes to an hour, however the exact length of time depended on interviewee availability. The team gave participants an estimate for the duration of the interview. However, the team extended the interview if a participant had more they wanted to share. Our team aimed to capture the feelings and perspectives of interviewees with substantial detail and accuracy. We happily extended our interviews and gave participants ample

time to share stories of their personal experiences if they felt so compelled.

The team determined the interview locations by convenience. Nineteen of the thirty-one interviews met at service provider buildings. Cafes served as a meeting place when we could not use the offices of service providers. Six of the seven cafe interviews included persons or families of persons with disabilities who do not currently receive support from service providers. Figure 3.2 shows the distribution of interview locations.

The number of team members present during each interview varied, however, every interview had three roles: lead interviewer, secretary, and translator. The lead interviewer led the conversation and ensured the conversation covered all topics in our guidelines. The secretary typed interview notes on a laptop. These notes acted as a failsafe in case audio recording equipment failed and included the secretary’s observations of interviewees’ body language and behavior. Finally, the translator served to facilitate the conversation between Albanian speakers and the American team. In some cases the interview participant would choose to speak in English. Nevertheless, an Albanian speaker still attended the interview to provide an element of familiarity and expanded upon topics if confusion arose.

Interviews all began in the same manner. The team initially requested consent from the interviewee to record audio and/or use the data from the interview in our report. During the first few interviews, the team used paper consent forms, found in appendices A, B, C, and D. However, the consent scripts caused confusion and the team opted to obtain verbal consent from participants during later interviews.

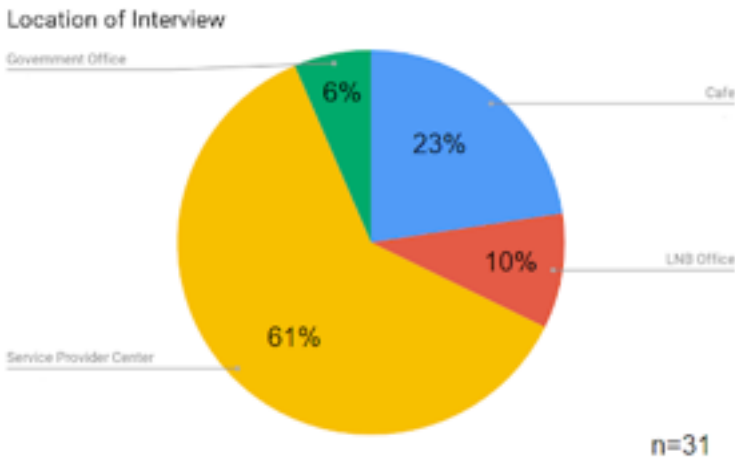


Figure 3.6: Distribution of Locations of Interviews

After acquiring consent, the lead interviewer began the conversation. Questions and flow of conversation changed depending on what the interviewee wanted to share and how they wished to share it. Due to the free-flowing nature of our interviews, the structure of the conversation differed for every interview.



Figure 3.7: Picture During Interview Conducted

3.2 Accommodating Special Needs During Interviews

The general interview guidelines for our unstructured interviews described in section 3.1 allowed us to hold conversations with all interviewees without disabilities. However, the team prepared alternate interview structures for persons with disabilities in

case situations arose in which a participant had limitations in verbal communication.

The primary factor affecting the individuals' ability to communicate was the presence of proxies, that is, people present during interviews who helped persons with disabilities communicate their responses to interview questions. Proxies were the parents of interviewees for five of our interviews, but

for three of the interviews a service provider staff member assumed this role. In eight out of fourteen interviews with persons with disabilities, parents or service providers participated in the interviews and answered questions for the person with the disability. Originally, the team intended to conduct all interviews with persons with disabilities without parents or service provider staff present. We wanted to encourage persons with disabilities to share their personal experiences without external interference because external influences can highly affect the responses of persons with ID when responding to interview questions (Corby et al., 2015). We had hoped to interview persons with disabilities alone to minimize the possibility of response bias, but for eight interviews a parent or a service provider requested to be present during interviews. The team consented to the wishes of parents and service providers to remain present during conversations. The team did not demand that parents or service provider staff leave the interview location because we feared this behavior could result in a lost interview opportunity. We followed our general interview guidelines, as mentioned in section 3.1 and appendix E, when interviewing persons with disabilities; however, the team secretary also noted the interjections of proxies. The team took these

notes into account when analyzing interview transcripts later on.

In one unique case, the team interviewed a person who had more limited verbal communication. The participant could clearly communicate yes and no responses through hand motions and sounds. To accommodate this need, the team used simpler yes or no questions and gave her the option of writing responses. In this case, the participant elected not to write and instead gave only yes or no responses to our questions. In all other interviews with persons with disabilities, participants were able to communicate verbally.

Originally, the team intended to include creative exercises in the interviews with persons with disabilities. We planned to ask participants to draw or sculpt aspects of their social inclusion, however disability experts and service providers suggested it would be more effective for us to gain qualitative data through conversation without any creative exercises. One service provider suggested that multitasking with questions and art would have been difficult for their service users with ID (E. Seiti, Personal Communication, November 4, 2019). In two interviews with persons with disabilities prior to the comments from experts, participants did take part in a drawing exercise, however

the remainder of the interviews did not involve any drawing or sculpting activities.

The team originally wanted to conduct multiple interviews with each person with disabilities. These interviews would have included a photo elicitation exercise. Team members would have asked participants to take photos of important parts of their lives between the interview sessions. Unfortunately, due to scheduling logistics only one repeat interview was possible. In this one case, the participant successfully completed the photo elicitation exercise.

3.3 Sample and Limitations

The Leave No One Behind Programme (LNB) gave us contact information for six service providers within Tirana, two disability experts, and representatives from the Tirana Municipality and from the Ministry of Health and Social Protection. From here we contacted families and individuals accessing the service providers through email invitations. In addition, LNB put us in contact with a project coordinator from the Albanian Disability Rights Foundation (ADRF). She helped us find four additional families to interview. The contacts provided by ADRF did not access supports offered by any public or private services at the time of the interviews.

The sample covered a wide variety of people, however our approach to gaining data presented several limitations. Due to the short time frame of our research, we only conducted 31 interviews. We originally wanted a purposive sample which represented an accurate depiction of the demographics of the disabled community in Tirana. Unfortunately, given our short time frame, we could not interview enough participants to claim our sample accurately reflects the demographics of the disabled community in Tirana.

This limitation prevents us from drawing accurate conclusions on the effects of gender or age on inclusion.

Figures 3.8 and 3.9 illustrate the distribution of interviewees with disabilities accessing public and private services, families' access to services, and the types of service providers we interviewed. Twenty-nine percent of the persons with disabilities interviewed did not currently access services. Other participants with disabilities attended either public or private service providers, as shown in the graphs. The types of services accessed by persons with disabilities and their families varied in the sample. However, only one of the seven service providers we interviewed identified themselves as a public service. This limited our understanding of the perspective from

Type of Service Accessed by Person with Disability

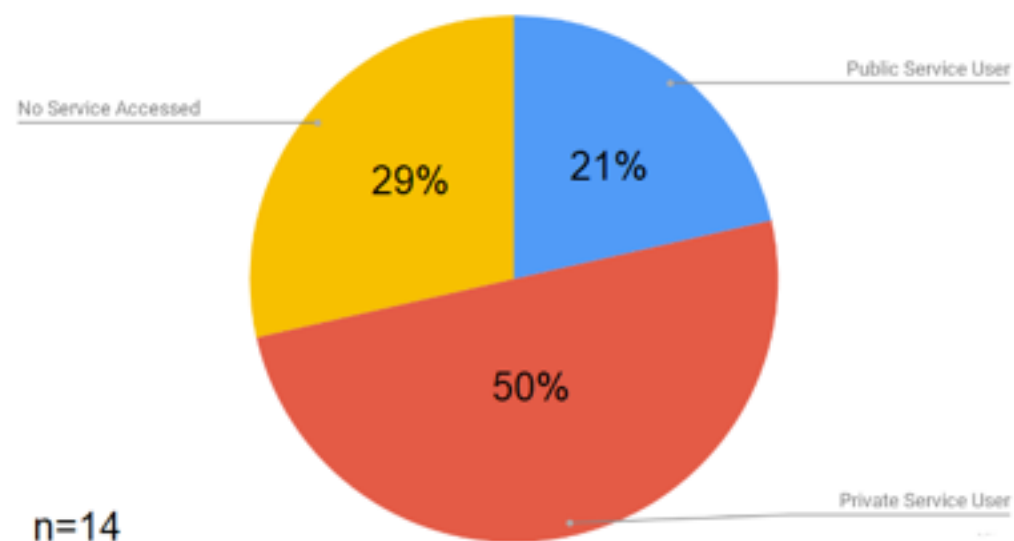


Figure 3.8: Distribution of Type of Service Accessed by Person with Disability Interviewed

Types of Service Accessed by Families of Persons with Disability

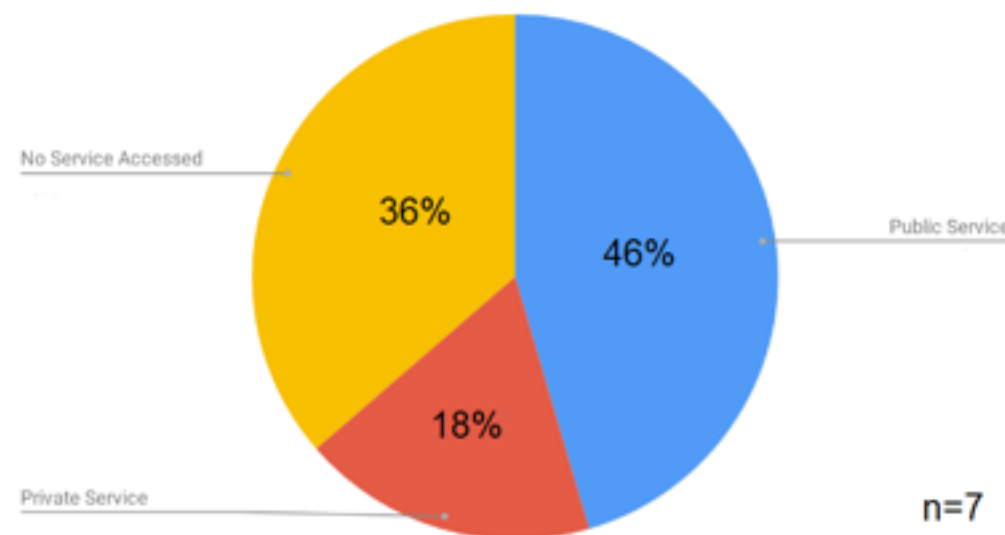


Figure 3.9: Distribution of Type of Service Accessed by Families of Person with Disability Interviewed

public service providers in Albania.

3.4 Methods for Analyzing the Data

Following each interview, the team secretary reread their notes and edited them for clarity before sharing the digital document with the team. The translator listened to the audio recordings from interviews and created one transcript per recording. The qualitative data for our research included both interview transcripts and secretary field notes.

Once the translator transcribed the interviews, the team read through the transcripts while underlining information related to significant themes. From our literature, we identified the following themes

to code for before reviewing transcripts:

- Community Interactions
- Employment
- Family Interactions
- Friendships
- Misinformation
- Proxy Interference
- School Experiences
- Service Provider Experiences
- Stigma

All team members coded each transcript individually to highlight what they found most important from each interview. The team then discussed the major themes and issues we had found in the interview transcripts and secretary notes. Our interviews revealed

themes we had not previously anticipated with our initial research questions. The team conferred with LNB to ensure our findings would still be useful to their program. With their support, we continued coding the remaining transcripts.

To visualize the information and see connections between themes, each team member wrote down important themes from interviews on sticky notes. We then connected all team members' notes to see large overarching themes deemed most significant by the entire team.

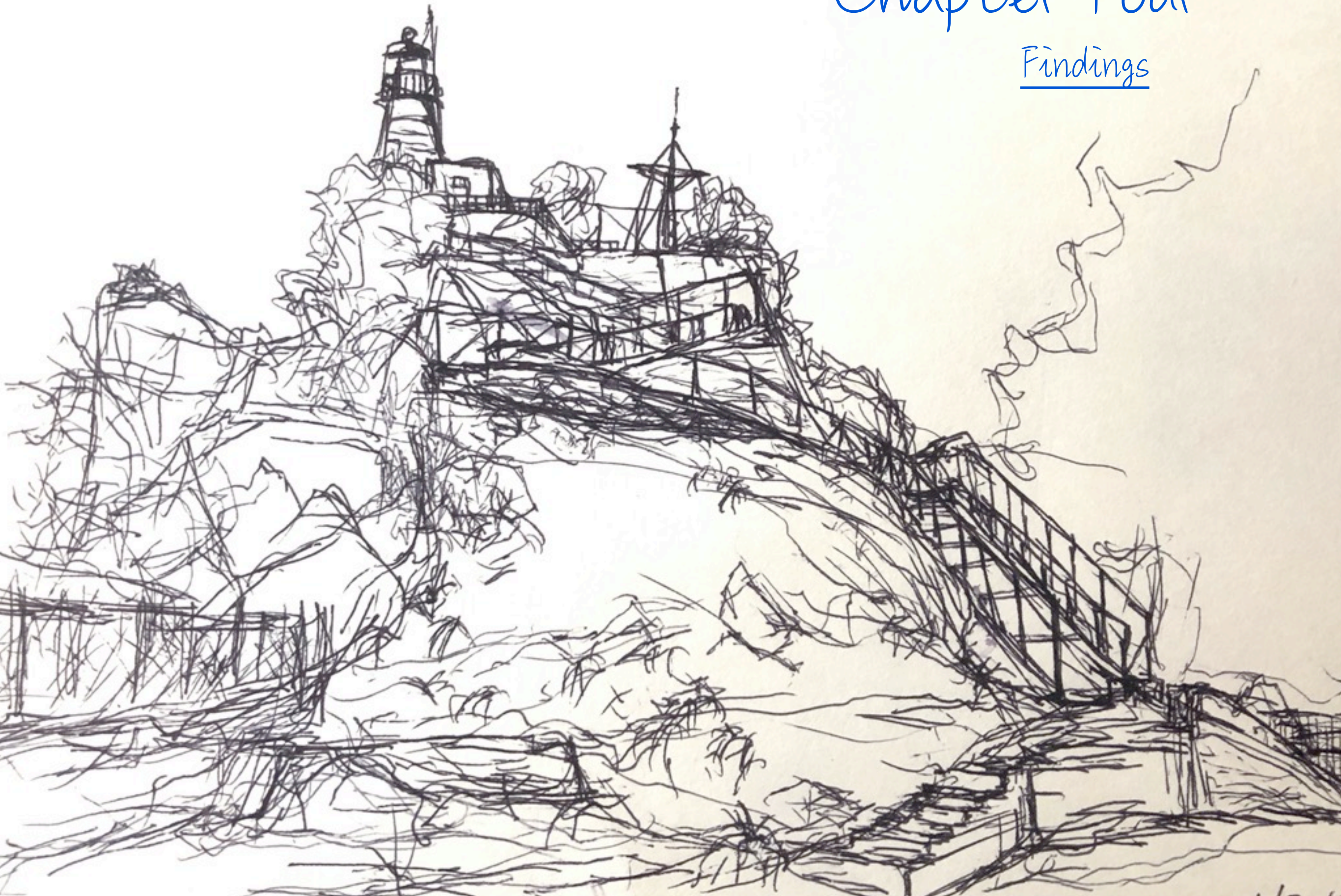
We highlight the major issues and themes which arose from the data analysis and team discussion in the next chapter, Findings.



Figure 3.10: Distribution of Type of Service Accessed by Person with Disability Interviewed

Chapter Four

Findings



Findings

The goal of our project was to document and assess the current state of social inclusion of persons with intellectual disabilities, developmental disabilities, and other neurological disorders in Tirana from the perspectives of persons with disabilities, their parents, social service providers, and government officials.



Figure 4.1: Two Team Members Working on Project

Our assessment of social inclusion guided us to suggest recommendations which aim to

promote the social inclusion of persons with disabilities in Albania. This chapter showcases information gained through our interviews. We organized our findings by important themes identified through the analysis of interview transcripts:

- Misconceptions about intellectual disability and Autism Spectrum Disorder
- Lack of proper inclusive education training for teachers affects school experiences for individuals with disabilities
- Social exclusion outside of service provider centers
- Complicated factors lead to discrimination
- Satisfying friendships within the service provider centers
- Existing service providers are insufficient
- Parents provide immense support for their children but can affect their child's self-advocacy
- Parents and service providers express dissatisfaction with the government's efforts in assisting individuals with disabilities
- Hopes and dreams of persons with disabilities which persist despite evident challenges

Section 4.1 includes a brief description of every stakeholder we interviewed. Each of the following subsections discuss one of the above themes. We use the quotes from persons described in Section 4.1 to support findings throughout this chapter. Most subsections begin with a brief narrative based on our interviews highlighting the main points of the theme. Following each narrative, we provide more examples and quotes from the interviews to support the main finding.

4.1 A Brief Introduction of the Cast

We obtained qualitative data through 31 interviews. The interviewees were comprised of five key stakeholders who impact the social inclusion of persons with disabilities in Albania: persons with disabilities, parents of persons with disabilities, service providers, disability experts, and Albanian government officials in the field of social work. However, persons with disabilities themselves provide the deepest insights into their feelings about inclusion. This section introduces the cast of interviewees to provide context to individuals' quotes included in later subsections. We changed the names of all interviewees to maintain confidentiality.

Individuals with Intellectual, Developmental, or Neurological Disabilities:

Armana: Armana is a 20-year-old with Down syndrome. She is currently in school and attends a private service center to receive therapies. Outside of school and the service center she participates in modelling competitions and dreams of being a professional model.

Artan: Artan is a 21-year-old male diagnosed with ASD. He is non-verbal and does not currently access any services. Artan grew up in Fushe Kruje and graduated high school. Since graduation, Artan mostly spends time with his family at home. He likes computers and enjoys spending time with his brother.

Avni: Avni is a male young adult who has disabilities a result of an accident he suffered earlier in life. Avni is blind and needs support to walk. He attends a private service provider and enjoys communicating with his international friends through social media.

Beni: Beni is a 20-year-old male diagnosed with ASD. He lived in Greece until the age of six when his family moved to Albania. Beni currently attends a vocational school to study information technology. He is not sure

what the future holds but hopes to work in computer networks and find a wife.

Besim: Besim is a male young adult with ID who attends a public service provider. He dreams of becoming a doctor.

Blerta: Blerta is a 33-year-old female with ID. Blerta attended a public service center when she was younger and now works as an office assistant. A disability advocacy group helped her find this job. Blerta enjoys watching television and making crafts in her free time.

Eli: Eli is a female young adult with ID who attends a private service provider for therapies. She likes to play sports and enjoys going for coffees with her sister in law.

Genti: Genti moved from Vlora to Tirana to live with his grandparents. He is in his early twenties and has an ID. Genti attends a private service provider daily. He likes to paint, cook, and watch movies in his free time. When Genti is older he wants to become a driver, pilot, or chef.

Gjeni: Gjeni is a 37-year-old female with ID. She attends a private service center to receive vocational training. Gjeni would like to live independently and own a house of her own in the future.

Michael: Michael is a 37-year-old with Down syndrome. Michael's mother died when he was young, and his father moved them to Tirana for better access to services. He attended an orphan service center, a psycho educational service center, and a special education school. Now he works for a printing company. He enjoys dancing, drawing, and performing impersonations.

Petrit: Petrit is a young adult with ID who attends a public service provider. He dreams of starting a family one day.

Roni: Roni is a young adult with ID. He has attended a private service provider since 2000. Roni attended public school for two years but was not able to continue his education after moving to Tirana. Despite his lack of formal education, Roni feels knowledgeable about the social service field and wishes to become a social worker someday.

Sokol: Sokol lives with his family in Tirana. He is 19 years old and has ASD. Sokol has not accessed any services. He attends school to study music and dreams of becoming a famous musician in the future. Sokol once performed in an exhibition for the commissioner of anti-discrimination in Tirana.

Xhovi: Xhovi is a 20-year-old with Down syndrome. He moved from the United States to Tirana with his family over a year ago. Xhovi's mother homeschooled him. He speaks both Albanian and English. Xhovi receives therapies and vocational trainings at a private service center. He works in a cafe but dreams of being a preacher.

Parents of Persons with Disabilities:

Artan's Father: Artan's father was present in the interview with Artan and his wife. Artan attended the interview but is non-verbal so his father and mother mostly spoke for him.

Artan's Mother: Artan's mother was present in the interview with Artan and her husband. Artan attended the interview but is non-verbal so his mother and father mostly spoke for him. Artan's mother is a teacher in her town, Fushe Kruje.

Beni's Mother: Beni's mother allowed us to speak to Beni separately from her.

Blerta's Mother: We interviewed Blerta and her mother together in the same interview. Blerta's mother was heavily involved in the interview, supplementing her daughter's answers with additional information.

Michael's Father: Michael's father was heavily involved in the interview with Michael.

He was very enthusiastic about Michael's accomplishments in life. Michael's father and Michael were both present in the interview.

Mother of five-year-old with ASD: We were not able to meet with her child. She spoke to us about her son who is attending a public service center, is non-verbal, and has some episodes of aggression.

Mother of 16-year-old with ASD: We were not able to meet with her child. She spoke to us about her son who is attending a public service center, is non-verbal, and has some episodes of aggression.

Mother of 18-year-old with ASD: We were not able to meet with her child. She spoke to us about her son who is attending a public service center.

Sokol's Mother: Sokol's mother allowed us to speak to Sokol separately from her.

Xhovi's Mother: Xhovi's mother allowed us to interview Xhovi separately from her.

Service Providers:

Private Service Provider A: Center focused on providing therapies to individuals with Down syndrome.

Private Service Provider B: Center focused on providing therapies to persons with

intellectual disabilities, developmental disabilities, and neurological disorders.

Private Service Provider C: Center focused on providing therapies to persons with intellectual disabilities, developmental disabilities, and neurological disorders. This center works with individuals who have more severe limitations due to their disabilities.

Private Service Provider D: Center focused on providing assistance to individuals with mental health issues.

Public Service Provider A: Center focused on providing therapies, vocational trainings, and activities to people with intellectual disabilities, developmental disabilities, and neurological disorders. This center also offers assistance to persons with mental health issues and elderly individuals.

Government Officials:

Government Official A and Government Official B: Albanian government officials working in the field of social services and social protection.

Disability Experts:

Disability Expert A: Doctor of social work at an American university specializing in disabilities.

Disability Expert B: Employee at Leave No One Behind with expert level knowledge on disabilities, especially intellectual disabilities.

Disability Expert C: Employee at a company specializing in the rights, employment, and capabilities of persons with disabilities.

4.2 Misconceptions of Intellectual Disabilities and Autism Spectrum Disorder within our Sample

Artan graduated from high school last year and is interested in computers. His family wants to find a vocational school to help him learn professional computer skills, but they are difficult to locate outside of Tirana. Artan is very good with computers and patterns. Artan has ASD. We asked if Artan had any dreams for the future and his mother, a teacher, asked us:

“Can I ask you, do you know what autism means?”

She did not think we understood the definition of ASD and further explained:

“[Persons with ASD] do not have the concept of time, or the concept of future, they just live in the present, and the now, they can’t know what they will do in the future”

Current definitions of ASD do not include any diagnostic criteria relating to an individual’s perception of time. ASD does not involve any impairments in cognitive functioning (American Psychiatric Association, 2013; World Health Organization, 2016). While ASD affects social and communication skills, persons with ASD can still participate in interviews. Artan read our consent script before signing his name to give informed consent. He acknowledged statements said by his mother during the interview and responded physically using body movements

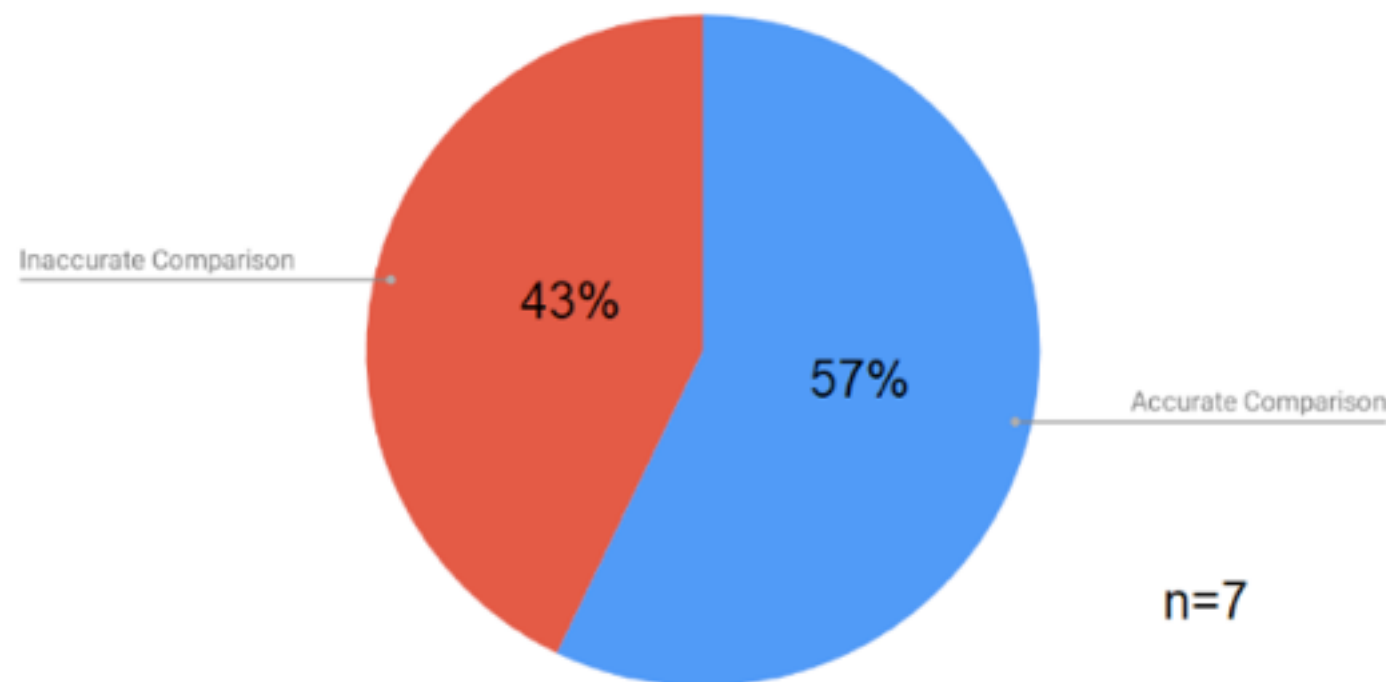
when mentioned by name. The team observed that Artan expressed himself nonverbally during the interview. Artan moved around in his chair, moved his hands, and displayed facial expressions when his parents acknowledged him. The team felt Artan could have answered questions for himself to some degree if his mother hadn’t interfered. Artan’s mother is a teacher and works in a school which educates both children with and without disabilities. However, her understanding of ASD does not align with modern definitions of the condition



Figure 4.2: Question Mark (images.pexels.com)

Figure 4.3: Incorrect Labelling of ID vs ASD in Interviews with Parents, Government Officials, and Service Providers that Discussed Autism

Incorrect Labeling of ID vs ASD in Interviews with Parents, Government Officials, and Service Providers that Discussed Autism



documented in guides used by healthcare professionals in both the United States and Albania (APA, 2009; World Health Organization, 2016). This finding supports Kulla's (2015) conclusion that teachers may lack information pertaining to ASD in Albania (Kulla, 2015).

“What is an intellectual disability?”

Government Official A inquired when our team asked about social service legislation for persons with ID. Based on the interviewee's tone and body language, this query seemed genuine. Government Official A did not appear to have a complete understanding of ID but nodded slightly in agreement when our translator mentioned

other specific conditions such as Down Syndrome and ASD. Everyone we interviewed had a connection to persons with disabilities, whether a legislator, service provider, or family member. Based on the coding of our transcripts, 43% of interviews that discussed ASD contained information which did not correspond with international guidelines for diagnosing persons with disabilities (APA, 2009; World Health Organization, 2016). One major area of confusion among parents and service providers was the differences between ID and ASD. In four interviews, someone explicitly stated ASD fell into the category of intellectual disabilities. Both the DSM and

ICD have separate sets of diagnostic criteria for these conditions as ASD alone does not involve impairments in cognitive functioning (APA, 2009; World Health Organization, 2016). The Albanian Medical Journal published a study, focusing on the rising rates of ASD in Albania. The conclusion of the study determined that ASD in Albania lacks research and should be further investigated (Shabani et. Al, 2013). Our findings support the conclusions from Shabani's (2013) study and further demonstrate that some people in Albania, even educators and service providers, do not have an understanding of ASD aligned with modern definitions (APA, 2009; Shabani et. Al, 2013; World Health Organization, 2016).

Staff at Public Service Provider A told us we would not get any useful information if we interviewed their service users with ID or ASD because they could not speak for themselves. Our team requested to speak with their service users nonetheless and had two brief conversations. During our conversations, the young adults were able to communicate to some degree and provided detailed information regarding their daily life. Our observations of these young adults conflicted with Public Service Provider A's perception of their service users.

4.3 Teachers Lack Inclusive Education Training Which Affects the Schooling Experience of Persons with Disabilities

“School life was terrible for [my son] ... they were not qualified to provide services for him”

stated the mother of Beni, a 20-year-old with ASD. Beni's mother described the difficulties her child endured in the school setting. She explained that her son's struggles arose because teachers did not understand how to work with his ASD in the classroom. She immediately opened up to us about these difficult times. When we interviewed her son separately, he was more reluctant to speak of his past. When we asked Beni about his time in junior high school he appeared very distraught, aggressively picking at his nails and looking down to hide what seemed to be some sort of embarrassment. Beni explained to us that he had no friends and was picked on during this time. He stated that his years of junior high school were “the worst years of my life as I can remember.”

According to Beni's mother, teachers mistreated her son in the mainstream education system. Beni's mother told us that when her son was five years old, “[teachers] closed him in a cabin.” According to Beni's

mother, the teachers placed Beni inside a cubby to deal with his behavior in the classroom.

She argued his teachers behaved in this manner because they were uneducated on how to handle Beni's differences. She claimed that first grade through ninth grade was “very difficult” for him. Beni continued to face discrimination in high school, where Beni's mother said, “the aspect of friends was not present at all.” Her description of public educator behavior is comparable to Kulla's (2015), who notes that Albanian teachers in public schools place children with ASD in separate rooms to “calm them down” (Kulla, 2015, p. 54). Kulla (2015) and Lika (2016) both further explain in their study findings that a lack of infrastructure and training exists for educators and specialists (Kulla, 2015; Lika, 2016).

During interviews with parents of children with ID or ASD, five out of seven parents claimed that teachers did not know how to work with their children. The mother of a five-year-old with ASD told us that teachers did not understand how to work with her child in the mainstream education system. The mother claimed:

“The teachers say they cannot work with him because they are not specialized for

his disability, he wants to move around, but the kindergarten does not allow him”

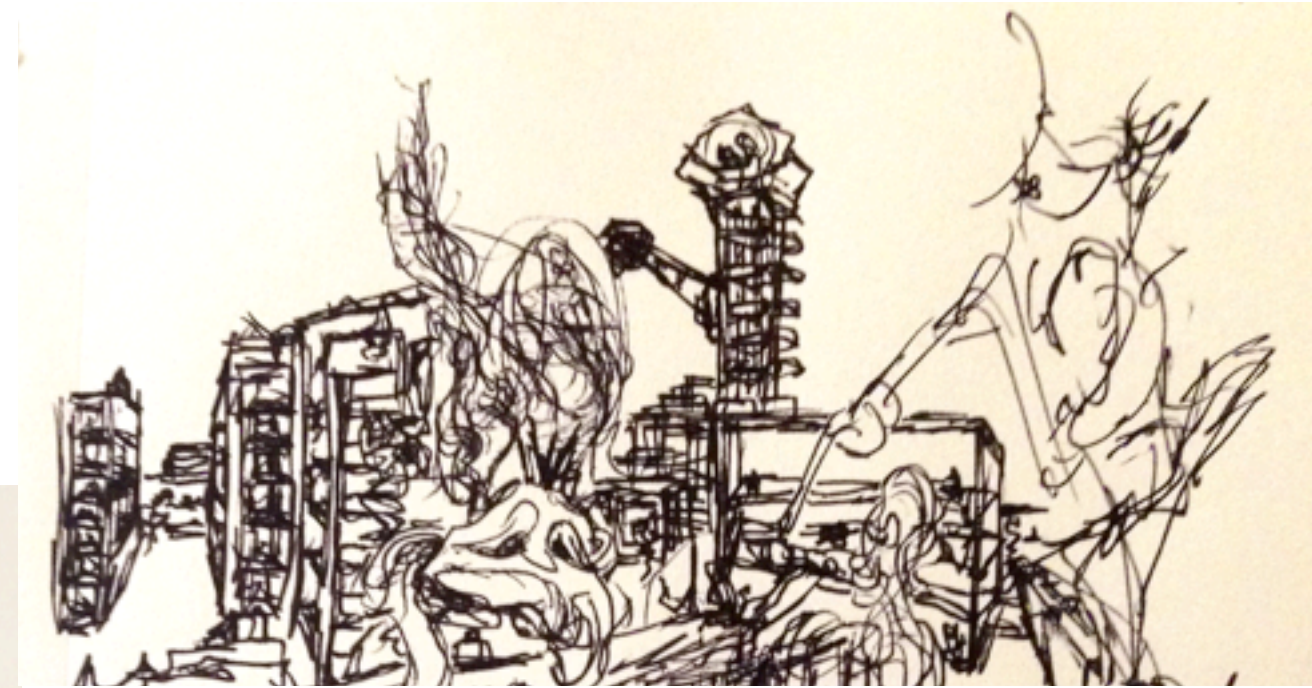
The teachers did not provide accommodations for this mother's son in the classroom. She claimed that this treatment from teachers negatively affects her son's education. When we asked his mother about his integration into the public-school system, she responded “they do not want to keep him at all ... they do not allow him to be included.” Blerta's mother claims that teachers in the public-school system were unable to work with Blerta who has an intellectual disability. When the team asked Blerta's mother how school has prepared her daughter for the future, she responded:

“The school has not provided any help, she only went for the first year, she was very active and energetic, she could not stay in one place”

The school system was unable to accommodate for Blerta's intellectual disability. Blerta eventually switched schools before she ultimately left the public-school system and began attending a public service center. Blerta's mother stated that her daughter's substandard education caused Blerta to experience disadvantages later on in life. Our findings from the perspective of persons with disabilities and their parents support the conclusions from previous

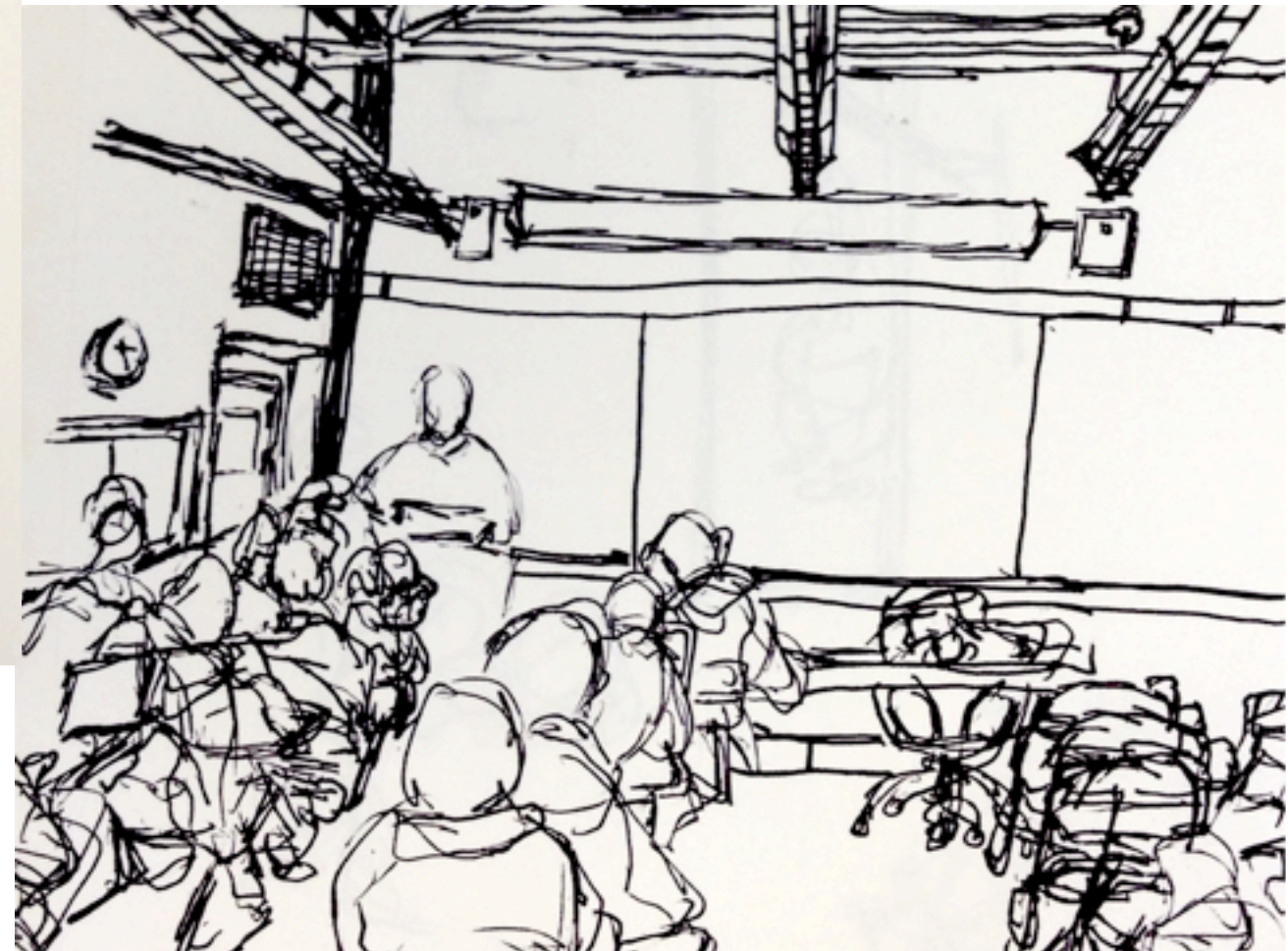


“In terms of bullying, that is a social problem happening, especially during junior high school years... these were the worst years of my life as I can remember”



“The school has not provided any help, she only went for the first year”

“School life was terrible for [my son]... they were not qualified to provide services for him”



“The teachers say they cannot work with him [my son] because they are not specialized for his disability”



Albanian studies which note that many teachers lack training pertaining to educating special needs students (Balla, 2015; Lika, 2016).

Our findings also suggest that the behavior of teachers towards special needs students influences the behavior of students towards their peers with disabilities. We spoke with the CEO of Private Service Provider C who has worked in the disability field for 33 years. She explained to us:

“When the teacher is included in the process of welcoming a new child and welcomes positively the child, it works better in terms of inclusion, because the class perceives the newcomer positively and the chances of inclusion increase. But if the teacher thinks that the child who has just come in is a burden in the class, the class perceives the newcomer as a problem and the inclusion becomes harder”

She suggested that teachers can heavily influence how students view their peers with disabilities.

4.4 Persons with Disabilities Experience Social Exclusion Outside of their Service Centers

Genti, a young adult with ID, skipped ahead of us into the common area of the center with apparent energy and excitement. During our interview, a staff member assisted Genti by repeating questions and occasionally calming Genti when he appeared stressed. This staff member acted as a proxy, interjecting at times but ultimately assisting and supporting Genti’s responses. Genti was rocking back and forth and rubbing his hands during the interview, but he said he enjoyed our conversation after we finished.

Genti mentioned he enjoys eating lunch with friends and expressed his satisfaction with friendships in the center. When we asked Genti if he had any friends outside the center, he described instances when children teased and bullied him:

“They tease, tease me, they do not play with me!”

When Genti voiced his concerns, he immediately looked down and began rocking more stiffly.

When the staff member asked if Genti wanted to play with other young adults outside of the center, Genti said, “No, I don’t want to.” When the staff member asked why not, Genti responded “because they tease me, and they make fun of me.” He told us he wanted to have friends outside the center

and even discussed a hypothetical situation where he could play ball games with friends in the future. Unfortunately for now, Genti has no friends outside the center and he doesn’t want to spend time with other children who do not have disabilities currently residing nearby. He has experienced bullying and only enjoys spending time with friends at Private Service Provider B.

Eight of the young adults we spoke with stated that they experienced some degree of mistreatment, whether by teachers, students or other people. Genti described an extreme case of mistreatment, explicit teasing and bullying from young adults without disabilities. In another interview, the mother of an 18-year-old with ASD told us about her son’s exclusion. She explained that her family members respect her son, but further explained that young adults without disabilities sometimes pity her son. She stated:

“[The children] feel pity, they look at him that he stays away from the football court, so he watches them”

Like Genti, this young adult had limited social inclusion. However, in this case, the mother attributed her son’s exclusion to pity, not teasing or bullying. Our team spoke with this mother of an 18-year-old with ASD at Public

Service Provider A while an administrator of the program was present at the table. This administrator explained that children without disabilities pity the children with disabilities and sometimes include them temporarily in activities. The administrator said:

“These are fragmentary moments, not that they include him, they feel pity, they accept the child in the game on small sequences, when the breaks are, in the form of pity rather than in a form of inclusion”

Both pity and bullying negatively impact the social inclusion of young adults in our sample. The CEO of Private Service Provider B acknowledged the difficulties with the social inclusion of persons with disabilities and claimed that “they [individuals with ID] are not included in social life.” She noted that there is a lack of integration for these children outside of the center.

Throughout our interviews in Albania, five of the seven parents expressed that their children with disabilities did not have friends without disabilities. Armana’s mother stated that her daughter with Down syndrome did not have friends outside the center setting at Private Service Provider A. Beni’s mother noted that her son with ASD has difficulties forming friendships with children who do not have disabilities. When we asked the director

at Public Service Provider A if any persons with intellectual disabilities have friends outside of their center, she replied:

“I don’t think they have, very rare they might have [friends outside the center]”

Eleven of the 14 persons with disabilities interviewed did not have friends outside centers or felt very lonely throughout the day. The lack of friendships for persons with disabilities is one factor contributing to their social exclusion in Tirana.

4.5 Many Complicated Factors Contribute to the Discrimination Towards Persons with Disabilities in Albania

Service providers, disability experts, and government officials we interviewed mentioned the stigma surrounding persons with disabilities in Albania. The persisting stigma is one factor contributing to the discrimination towards persons with disabilities in Albania. Government Official A stated:

“Our society, want it or not, is stigmatized”



Figure 4.5: Sketch 7 By Natalie Milgram

Half of the service providers and organizations interviewed explicitly mentioned stigma or discrimination of persons with disabilities and mental health issues in Albania. The CEO of Private Service Provider B claimed that persons with disabilities are “one of the most discriminated against categories in Albania.” Similarly, Disability Expert C stated “they [people with ID] consist as one of the most discriminated groups in society... persons with intellectual disability are amongst the most discriminated.” During a different interview, Private Service Provider D was quite vocal with his opinion on the evident stigma surrounding persons with disabilities

in Albania. During our conversation in a local cafe, this service provider spoke for nearly an hour straight voicing his concerns with the mental health care system and treatment of persons with disabilities. The service provider spoke of a connection between stigma and perception, mentioning misconceptions which may lead to inaccurate perceptions of persons with disabilities. He stated:

“Community is a main concern. In our place in the neighborhood stigma was so high. We tried to reduce stigma. The families were asked to do volunteer work to benefit the neighborhood. By demonstrating helpful skills, it would change peoples’ expectations”

Private Service Provider A talked about a similar topic, explaining that service user involvement within the Albanian community helps persons without disabilities become more familiar with persons with disabilities. She explained:

“We do these types of activities to show that there is nothing different and that [persons with disabilities] can be of use to society”

These service providers felt that interactions between persons with and without disabilities helped to reduce stigma by

allowing people without disabilities to better understand the persons with disabilities. These statements from service providers relating to community involvement to reduce evident stigma echo the findings of Siperstein, Parker, Bardon, and Widaman in their 2007 study on middle school interactions between students. These researchers found that forced exposure between middle schoolers with and without disabilities could help students without disabilities better understand students with disabilities, reducing the stigma formed by misconceptions over time (Siperstein, Parker, Bardon, & Widaman, 2007). While the school setting in Siperstein’s study provides more prolonged interactions between persons with and without disabilities, the service providers’ comments suggest that even periodic interactions between persons with and without disabilities helps to reduce stigma.

While several young adults, parents, service providers, and government officials acknowledged and described specific examples of discriminatory behavior, six persons with disabilities interviewed claimed they had never been discriminated against. For example, when we spoke with one young adult with Down syndrome, Xhovi, he said he liked Tirana. Xhovi told us that Tirana is “a big place, you meet people here, big people here. It’s like New York.” Xhovi moved from

the United States to Albania with his parents. He attends Private Service Provider A every weekday to receive development therapy. Xhovi was extremely friendly and talkative during our interview, appearing very open with his thoughts on social inclusion. We asked Xhovi if everyone was nice to him in Tirana and he said yes. Xhovi agreed that individuals in Tirana were nice.

Our team got the chance to speak with Xhovi’s mother later on in our research. We spoke with her at a local cafe separately from Xhovi. She denied any experiences of discrimination or mistreatment towards Xhovi, but she added some additional context. She felt that their American roots made them less of a target for discrimination. She described instances where other Albanian mothers spoke to her about their children’s mistreatment and discrimination, but she explained that her affiliation with the United States resulted in less negative treatment towards Xhovi.

Artan’s mother also denied any discrimination towards her son with ASD. When we asked whether Artan has faced discrimination, she stated:

“He has not faced any discrimination, they all knew him, it is a small village, they were friendly and loving”



*"I call them as one of
the most discriminated
categories in Albania"*



*"In our place in the neighborhood
stigma was so high"*

*"Our society,
want it or not, is
stigmatized"*



*"They [persons with disabilities] consist as one
of the most discriminated groups in a society
lacking the implementation of human rights
and their inclusion"*



Figure 4.6: Collage of Sketches By Natalie Milgram and Quotes from Interviewees About Stigma and Discrimination

Like Xhovi's mother, Artan's mother mentioned that from her perspective there is no discrimination or bullying. Artan's mother noted that there is pity in Albania, but she further explained that she has not observed particular instances of children without disabilities discriminating against students with disabilities in the school where she teaches. In a similar case, one mother of a 16-year-old with ASD denied any discrimination of her son. She lives in a smaller village and accompanies her son everywhere. When we asked her about discrimination, she said:

“No, we did not have any cases, I am always with [my son], I have accompanied him through all the activities we have never faces forms like this”

During this interview, the mother was speaking in the public space of Public Service Provider A. The administrator of this service provider was present. During our interview, the administrator chimed in when the mother gave this response to the team's question on discrimination. The administrator stated that:

“The case of [this individual] is unique, because his mother has always accompanied him throughout all his activities, she has never left him alone to face discrimination”

This administrator suggested that the mother's case was an outlier. Our findings suggest that stigma and discrimination towards persons with disabilities still occurs in the greater Tirana area.

4.6 Persons with Disabilities have Satisfying Friendships Within Service Provider Settings

We spoke with one young adult with ID, Roni, who enjoys spending time with his friends at Private Service Provider B. Roni likes to celebrate his birthday at home with both family and friends from the center. Roni told us that the center is a big part of his life, claiming that he only feels comfortable at Private Service Provider B or with family, stating

“I don't have any other places despite the center and my family”

Additionally, Roni expressed satisfaction with his experiences at Private Service Provider B:

“I like to be [at the center] because I do a lot of things that make me feel happy and powerful”

Roni found refuge in the center after a public high school did not accept him. Roni did not pursue a formal private education and

instead elects to take classes at Private Service Provider B. Roni is satisfied with the friends he has but would like more. Although Roni desires more friends, he finds it hard to meet new people. He stated:

“I would like to have more [friends], but I feel comfortable with the ones I have already, the ones who know me as a friend ... they have it easier to communicate with me and I have it easier to work with them rather than starting again from the beginning, which is going to be even more difficult”

Eleven of the 14 persons with disabilities in our sample attend a public or private service center regularly where they receive development therapies such as art therapy, vocational training, social skills training, and music therapy. We found that all interviewees with disabilities accessing service providers felt content with their inclusion within their service centers. Both Armana and Xhovi, 20-year olds with Down syndrome, are satisfied with their friendships at Private Service Provider A. When we had asked Genti about his friendships at Private Service Provider B he said:

“Yes, I like, I like to stay with my friends, I will stay with friends, yes”

The attitudes of service providers aligned closely with those of the persons with disabilities we interviewed. Every service provider we spoke with stated that their service users have satisfying friendships within their center. The director from Public Service Provider A claimed that persons with disabilities have very good relationships with each other. She stated:

“[Persons with disabilities] have very good relationships, they collaborate with each other, they know each other, but even for the new ones they have very good relationships, we haven’t had any cases that they had arguments”

Public Service Provider A believed that their service users with disabilities have good relationships inside their center. All other service providers we interviewed shared a similar opinion, further supporting our finding that many persons with disabilities have satisfying friendships and feel socially included within their service provider setting.

4.7 Existing Services are Insufficient and Inaccessible

We met with the mother of a five-year-old with ASD who attends a public center. The mother cried as she reflected on her life. She spoke to us about the difficulties she and her

son face. This mother spoke of the services that are available for her child, stating:

“In private centers, I cannot afford it... so I send him in public centers. The public centers do not offer the correct process of therapy. When my son starts crying, they send him out”

This mother can only afford public services but claimed they do not have well-trained staff or good quality therapies. As a result of this, the mother says, “he [my son] does not like to go in the therapy.” She was visibly upset when stating that there is no affordable care of good quality for her child. This mother claims that she has “requested three times for a special teacher but my request has not been answered.” When we asked about her son’s future, she responded:

“I hope his situation will be better, because the possibilities are very limited”

She said this situation is similar for many other persons with ID and ASD in Albania. Throughout our interviews, the group found that all parents of children who attended public services were unhappy with the current supports available for their children. The parents of children currently attending private service centers did not express any dissatisfaction with the available services during our interviews. Blerta, a 33-year-old

with ID, had attended a public service center earlier in life. Blerta’s mother expressed dissatisfaction with the availability of services for her child. She claimed:

“There is nothing. I have asked for services at the local service office and at the municipality, but none of them gave information about anything. No information about payment or other benefits that disabled people might be entitled to receive”

Blerta’s mother has been unable to locate appropriate services for her daughter. She believes the services should be more widely available for people with intellectual disability. In our interview, she told us that parents are very busy and find it difficult to care for their children all day long. Blerta’s mother is worried about her daughter’s future. She is concerned that Blerta will be left behind with no services once she dies. She stated:

“We are here today, but not forever, what is going to happen after we are not here anymore?”

Like Blerta’s mother, Artan’s mother noted dissatisfaction with the available services to support her son with ASD. Artan does not currently access services. His mother is aware of some services, but given her

"I thought, what will happen later with [my son] when I won't be here?"

"We are here today, but not forever, what is going to happen after we are not here anymore?"



"In private centers, I cannot afford it... so I send him in public centers. The public centers do not offer the correct process of therapy. When my son starts crying, they send him out"



"There is nothing. I have asked for services at the local service office and at the municipality, but none of them gave information about anything"

"I don't know what services there are in the community, I don't have information on that"



location of residence, she felt the long commute would be too difficult to manage. She stated:

“They build centers where no one can go, they are maybe not interested in this area”

Blerta’s mother was unaware of existing services while Artan’s mother could not transport her child to and from the existing center she was aware of. The team visited five service providers to conduct interviews. While these service providers attempt to support persons with disabilities and their families, our findings indicate that some parents of persons with disabilities are unaware of the existing services or feel the existing supports are insufficient or inaccessible.

4.8 Parents Provide Significant Support but can Affect their Child’s Self-Advocacy

Our team wanted to hear directly from Michael about his thoughts on social inclusion, but we instead learned of Michael’s life story first and foremost from his father’s perspective. Michael’s father became teary eyed when he told us Michael’s mother passed away when Michael was only six years old. He told us Michael had been an orphan and said:

“Excuse me for the emotions, what I am going to say now is the most important thing, my wife before she passed away, she left me her last wish, to help [Michael] to become strong”

Michael’s father explained how he brought Michael to Tirana and sent him to a psychoeducative residential center. Later on, Michael’s father coordinated vocational training for his son, which enabled Michael to gain employment at a publishing company. During our interview, Michael’s father became very emotional at times, demonstrating his love and compassion for Michael. Michael’s father was, and still is, a large source of support for Michael in many aspects of his life. His father told us:

“He never goes out without me, apart from when he goes to work, he goes alone to work and comes back home alone. This is happening because I have a responsibility for him, also, people in the street might tease him as well, this is a diverse society, and I am afraid that someone will tease him”

Michael’s father travels with his son out of fear for Michael’s safety. He provides a safe, loving, and comfortable living environment. He told us:

“[Michael] has his own room, his own TV, and everything that can make him feel happy”

Michael’s father also spoke to us about his son’s evident talents in imitation, painting, and dancing. He appeared extremely proud of his son, emphasizing Michael’s qualifications on a CV [Curriculum Vitae] and complimenting Michael’s physical features:

“I love your eyes [Michael], you have the most beautiful eyes!”

While Michael’s father clearly loves his son and is extremely proud of Michael’s accomplishments, at times the team found Michael’s father was not letting Michael speak for himself. When we asked Michael questions, his father often interjected or spoke on behalf of his son. At one point during the interview, one team member momentarily distracted Michael’s father with some questions. During this period of time, another team member tried to talk to Michael directly about his own personal values. We learned from Michael directly that he enjoys going to the artificial lake, drinking coffee and tea, and going out to the theatre and the cinema. Michael told us that he values good people, having good people in his life. When we asked him what makes a good person, he responded:

“Love, loving, that gives love, to have a good heart, to be like brothers and sisters, to be together, supportive”

The team observed that Michael was capable of clearly communicating his thoughts verbally. Five other parents spoke for their children during interviews. Armana’s mother tried to encourage her daughter to speak during our interview. We had met Armana, a 20-year-old with Down syndrome, and her mother at Private Service Provider A. At first, Armana seemed shy and was hesitant to speak without her mother’s encouragement. Like Michael’s father, Armana’s mother provides Armana with significant support throughout the day. Once her mother left the table, Armana quickly began to speak to our translator in Albanian. Later, our team learned that Armana had been speaking about her interests in modeling to our translator. Our team noticed that once Armana’s mom returned to the table, Armana became softer spoken and more hesitant in producing responses. At one point, we asked about Armana’s friends and Armana told us she had friends she enjoys spending time with. At this point in the conversation, Armana’s mother became more tense and frowned as she said that Armana has no friends outside of Private Service Provider A.

This interview had a complex family dynamic. Armana appeared shy and stressed at times during our conversation. Armana’s mother seemed to care deeply for her daughter but, like Michael’s father, spoke for her child at times. Armana seemed willing to voluntarily communicate with our translator once her mother left the table. Like Michael’s father, Armana’s mother was extremely proud of her child’s accomplishments. After our interview, Armana’s mother showed us videos of Armana’s modeling performances and encouraged Armana to perform a live modeling demonstration for us. We watched Armana stride up and down the cafe, smiling as she struck poses at the end of our makeshift “runway.”



Figure 4.8: Sketch 8 By Natalie Milgram

The team observed that all parents present during their child’s interview spoke on behalf of their child to varying degrees. These parents in our sample provide significant support to their children but sometimes speak for their child or limit their child’s ability to express themselves. In these cases, parents sometimes believed their child could not communicate for themselves. Additionally, the team observed that particularly stressed or emotional parents were more likely to speak over their children. When the team interviewed young adults without their parents, the individuals expressed themselves more freely and provided more detailed responses. On the other hand, interviews with persons with disabilities and their parents together resulted in much more complex family dynamics, often with parental interference which hindered their child’s communication. Artan’s mother believed her son with ASD could not answer questions for himself. However, the team believes that Artan understood our interview questions because we observed that he nodded and displayed other physical reactions in response to questions. Blerta’s mother spoke for her daughter with ID at times when we tried to interview them together, but she also provides immense support for her Blerta, advocating for services and providing a supportive and safe living environment.

Previous research has documented the complicated roles of parents who have children with disabilities. Our findings support Rushe's (2015) conclusion that parents offer significant support to their children with disabilities and care deeply about them (Rushe, 2015). Furthermore, other studies have found that parents speak for their children with disabilities. Our findings on parental interference compare to those of Pilnick (2011) who noted that parents spoke for their children during Individual Education Program meetings in the United States (Pilnick et al., 2011). During our interviews with service providers, staff members noted their observations of complex family dynamics. Private Service Provider B told us that parents of persons with disabilities don't fully understand their children's capabilities. Furthermore, the parents are surprised when they observe their children performing tasks in the center, they do not usually complete at home independently. The administrator of Private Service Provider A told us:

“Parents sometimes feel surprised by their children’s talent because they have other expectations for their children”

This service provider went on to explain that sometimes parents had misconceptions about their own child's abilities. She stated:

“There have been cases when the parent was against the talent of their child”

To counteract the parent misconceptions, Private Service Provider A explained that she invites parents to witness their child's skills. She told us:

“We invited their parents as well in order to demonstrate the skills of their children. In this way their parents understood what their children’s skills were so they could support them more to make their children’s dreams a reality”

In another interview, Disability Expert C provided additional context to the role of parents with persons with intellectual disabilities. She told us about the Albanian legislation which encourages other people to speak on behalf of persons with intellectual disabilities. She told us:

“For persons with intellectual disability, so far they cannot speak for themselves, but their caregivers make decisions on their behalf. This is also stated in legislation which needs to be abolished, in the legislation it is stated that the parents and carers take decisions of the lives of persons with disabilities”

This disability expert referenced the law on substituted decision making for persons with disabilities which is one component of the law on the “Accessibility for and Inclusion of Persons with Disabilities” (“Accessibility for and Inclusion of Persons with Disabilities,” 2016). Disability Expert C argued that this law interferes with self-advocacy rights for persons with disabilities in Albania. Additionally, she described her efforts as a disability expert to work with local organizations, where she offered training to their self-advocacy groups. The CEO of a private service provider told us:

“The advocacy of [persons with disabilities] has been done by their parents and not the youngsters themselves, so far by now their rights have been protected by their parents, but we have initiated a self-advocacy group where the youngsters advocate for themselves”

The team observed that this self-advocacy training helped Service Provider B promote self-advocacy for their service users.

Quotes from Parents and Service Providers

*“There is a lack of proper expertise and **there is a lack of willingness** compared to the lack of expertise which makes it harder to implement laws that they adopt”*

*“Law has indicated what should be done, but **no one** is implementing the law”*

*“The government **should take actions** for our children”*

*“They [persons with disabilities] are not respected as other people, they **have not been considered seriously** or taken into account by the government”*

*“The government has to put **more efforts** into in the area of inclusion of persons with disabilities”*

Quotes from Albanian Government Officials

*“**We continue to work**, what is positive and what we see as progress is that society is generally more aware and acceptive, but it remains as an issue and **we should work more**”*

*“Based on the standards that we have, **we monitor the implementation** of their services”*

*“We are **trying to provide** as many services as we can”*

*“**I have advocated** for the protection of vulnerable groups, strategies and legislation for all the vulnerable groups who need protection and face economic difficulties, persons with disabilities”*

*“Persons with intellectual disabilities are the most challenging group, therefore, there are more difficulties, we have put them in the **center of our attention**”*

Figure 4.9: Quotes from Service Providers and Quotes from Albanian Government Officials

4.9 Stakeholders Express Dissatisfaction Towards the Albanian Government's Efforts in Supporting Persons with Disabilities

Throughout the course of our research, no interviewees expressed satisfaction with the government's attempts to assist persons with disabilities in Albania. An administrator of Private Service Provider D stated:

“We see that in government and local authorities the priority is not mental health, mental health is far behind”

He claims the government does not prioritize mental health and stated that the government views persons with mental health issues as “toxic waste.” He told us the Albanian government views persons with disabilities as second class and argues that the government does not make an effort to assist this group. He stated:

“Law has indicated what should be done, but no one is implementing the law”

There remain difficulties with the implementation of legislation supporting persons with disabilities in Albania (Private Service Provider D, personal communication, November 8, 2019). The National Action Plan

for Persons with Disabilities in Albania will remain in effect until 2020, however 13 interviewees still expressed their dissatisfaction with the Albanian government's efforts in supporting persons with disabilities.

We spoke with Disability Expert C who is very familiar with the laws protecting people with disabilities in Albania. She said that the government is not qualified to assist people with intellectual disabilities, stating:

“There is a lack of proper expertise and there is a lack of willingness compared to the lack of expertise which makes it harder to implement laws that they adopt. They try to copy paste or use the international standards, despite the efforts of civil society to explain and provide the necessary information and expertise”

When we spoke with Disability Expert A, she agreed that the government lacks qualifications to assist persons with disabilities in Albania. Disability Expert A argued that Albanian legislation follows the principles set forth by the United Nations Convention on the Rights of Persons with Disabilities to comply with the international standards required for Albania to gain

admission to the European Union. However, she suggests that the Albanian government does not effectively implement this well-written legislation because they do not understand the wording and principles of their own policies. She stated that the Albanian government does not prioritize persons with disabilities. Similarly, Public Service Provider A expressed dissatisfaction with the government. She said that there is a lack of staff and the facility is very outdated due to a lack of government funding. She noted confusion on which services her center should be providing, stating:

“We are a multidisciplinary center, we do not focus only on persons with disabilities, therefore, we need a specific legislation to clarify what this center should do”

While many interviewees noted their dissatisfaction with the Albanian government, we interviewed two government officials in the field of social services who explained their current efforts and challenges in implementing the legislation which supports persons with disabilities. Government Official A spoke of their efforts to support persons with disabilities and said, “We are trying to provide as many services as we can.” Government Official B spoke more about the current policies assisting

persons with disabilities in Albania. She explained that the government is working to promote the social inclusion of persons with disabilities but noted the difficulties. She stated:

“We continue to work, what is positive and what we see as progress is that society is generally more aware and acceptive, but it remains as an issue and we should work more”

Government Official B was aware that key stakeholders such as service providers are not satisfied with their current efforts to promote the social inclusion of persons with disabilities. Both government officials stated their efforts to improve the implementation of legislation but did not provide specific examples of what these efforts entail. They provided little detail when we asked about the challenges in implementing legislation, however Government Official B claimed the lack of financial resources hinders the progress of the National Action Plan’s implementation. She stated policies in this plan are difficult to implement due to their associated cost. The team observed differences between the opinions of service providers and government officials, highlighting the complexity of implementing legislation and funding social services in Albania.

4.10 Despite Challenges, Young Adults with ID and ASD Still have Dreams for the Future

“I want to become a driver... and a pilot... also cooking, all the things I like!” – Genti

“My dream is to be a social worker, and my experience has helped me a lot to achieve this” – Roni

“Preacher... my friend is a preacher. I want to be a preacher like him” – Xhovi

The young adults in our sample told us their dreams for the future, but an administrator from Public Service Provider A expressed a more pessimistic view towards the futures of her service users. During an interview with a mother of an autistic child, the administrator of Public Service Provider A was present to provide supplemental information as necessary. When the team asked about the mother’s desires for her son’s future, she answered that she hopes her son gains more independence as he matures. After this mother’s response, the administrator added some additional commentary, stating:

“I don’t want to intervene, but I know the family, and the child, and other elements and factors that might consist in the future of these children, there is no hope

about future careers and of something that they can hope in terms of their dreams”

The administrator claimed that this individual could not gain independence because of the limitations from his disability. This administrator’s comments provided a different perspective than that of the persons with disabilities we interviewed. The young adults in our sample expressed a wide variety of interests and dreams for the future. Eight young adults communicated their interests in the arts and mentioned that they enjoyed activities such as drawing, painting, cooking, singing, and playing instruments. Other participants mentioned interests such as sports, computers, shopping or crafts. Often, the interviewees began to smile when they spoke of their interests and individual talents. For example, Genti, a young adult with ID, stated “I like painting, I do paintings, I do, painting is my most favorite subject.” During his interview, Genti appeared proud when the team requested to take photographs of his paintings. He replied with many enthusiastic yeses and seemed satisfied with our interest in his visual artwork. Genti said that he wants to be either a driver, pilot, or chef later in life.



"I want to become a driver... and a pilot... also cooking, all the things I like!"



"I want to find a girlfriend, that might be my wife in the future"



"My dream is to be a social worker, and my experience has helped me a lot to achieve this"



"My goal is to become famous in music, to be a famous singer"



Figure 4.10: Collage of artwork from individuals with disabilities

On a separate occasion, Sokol, a young adult with ASD, brought along a guitar to his interview and spoke with us about his passion for writing, playing, and performing music. He told us:

“My goal is to become famous in music, to be a famous singer, to earn a lot of money, and go in clubs”

Sokol currently works towards his goals by improving his musical skills through courses at Liceu Artistik. He told us he enjoys studying music for fun and stated:

“Music is like a natural instrument for me. I like to play music, especially for Pink. I play music and sing very well”

While Sokol sang for us during his interview, two other young adults also demonstrated their talents including modelling and dancing. Another young adult, Roni, said that he wants to be a social worker in the future. He helps staff run programs at Private Service Provider B and teaches in class when the teacher is not present. Roni communicated that his experiences helping others at Private Service Provider B contribute to his progress in becoming a social worker. While Roni lacks friendships outside the center, he feels supported by the staff at Service Provider B, stating:

“Yes, people are helping me, the people around me have promised me that they will help me, for example the course we are doing for independent living is going to help me to be independent, even if I do not have an official qualification for a social worker, my dream is to be a social worker, and my experience has helped me a lot to achieve this, also, the center will help me to do that, they have promised me that they are going to help me”

Roni told us about his current romantic relationship, stating:

“The happiest thing is my relationship with my partner, and I feel very in love in this relationship”

Three of the young adults in our sample expressed interest in romantic relationships and wanted to start families of their own. For example, Beni, a 20-year-old with ASD, is currently studying computer programming and told us:

“I want to find a girlfriend, that might be my wife in the future”

Beni explained that he wants to focus more on finding a girlfriend because it's a permanent friend that will be there forever in his life. He told us that it “is easy to have random friends,” however he emphasized his long-term goal of developing a permanent friendship in the future. Our findings suggest that while discrimination and misconceptions about disabilities remain, persons with disabilities persevere through life. They attempt to preserve their dignity and rights as humans by voicing their thoughts and wishes when possible. They strive to reach their goals and dreams despite the challenges faced.



Figure 4.11: Collage of artwork from individuals with disabilities

Chapter Five

Recommendations & Conclusion



Recommendations and Conclusion

Our recommendations aim to provide the public with more information pertaining to disabilities and encourage interactions between persons with and without disabilities. More available information may reduce stigma and more interactions between persons with and without disabilities would provide opportunities for persons without disabilities to witness the competence of persons with disabilities, potentially changing the public's perception towards persons with disabilities in Albania (Haddad, 2015; Siperstein, Parker, Bardon & Widaman, 2017). Our recommendations are organized into three subsections: future research, information sessions and trainings, and community interventions.

5.1 Future Research

When people observe a displayed difference in an individual, stigmatization of the individual can be more likely if the observer is uninformed on the cause or nature of the difference. For example, persons unfamiliar with the behaviors of individuals diagnosed with ASD may fear them due to the lack of information (Haddad, 2015). In Albania, as in other countries, the uncertainty surrounding ID and ASD contributes to negative

perceptions which can result in discriminatory behavior towards these populations. Future research can help to educate society which may reduce stigma and improve social inclusion for persons with disabilities in Albania. Specific recommendations for future research topics within Albania include:

1. Autism Spectrum Disorder (ASD)

We recommend research which documents the current understanding of ASD from the perspective of teachers, parents of persons diagnosed with ASD, and service providers. Our findings and personal observations suggest that persons in Albania lack information on ASD. Documentation on teachers' current understanding of ASD would help the Ministry of Education develop more effective trainings for educators. We also suggest that future disability research in Albania considers the opinions of the persons with disabilities themselves. This research would encourage self-advocacy and independence of persons with disabilities, valuing their human rights in the process.

2. Specific Demographics Regarding Persons with Disabilities in Albania

We recommend research which documents the precise number of persons diagnosed

with ASD, ID, and Down Syndrome in Albania since there is currently no documentation on this data. We also recommend research which documents the area of residence for these populations. More updated disability demographics would help the government determine optimal locations and services of future service providers.

5.2 Information Sessions and Trainings

While future research can educate the public on disabilities, formal trainings would more effectively provide teachers and parents with information relevant to their specific needs.

1. Information Sessions for Parents

Our sponsor, LNB, has facilitated many information sessions for service providers. These workshops help to promote social inclusion for persons with disabilities in Albania. We suggest that LNB continue these service provider trainings. We further recommend that LNB or service providers hold future information sessions to educate the parents of persons with disabilities. Parents often act as an advocate for their child when requesting services, however parents also spoke for their children with disabilities during interviews when we observed the individuals were capable of expressing themselves. We suggest that

information workshops through LNB or service providers further educate parents on their child's diagnosis. Additionally, to supplement the workshops, service providers could distribute informative pamphlets or email information which educate the parents of their service users on the specific impairments associated with different conditions.

2. Trainings for Educators on Inclusive Education for Persons with Disabilities

We recommend that the Ministry of Education facilitates additional trainings in public schools to educate teachers on working with persons with ASD. These trainings should explain the best practices for managing challenging behavior of special needs students. Additionally, trainings should discuss techniques for educating and communicating with students with ASD, ID, and other developmental disabilities. Teachers in public schools may also benefit from more hands-on training in which disability professionals demonstrate techniques to work with special needs students in the general education classroom.

We recommend that these trainings encourage teachers to welcome students with disabilities into their classrooms. Negative views from educators can cause

students without disabilities to form negative perceptions of their peers with disabilities (I. Trajani, personal communication, November 8, 2019). We emphasize the important role of teachers in aiding social inclusion for persons with disabilities. Perceptions of persons with disabilities begin forming during childhood (Bornstein & Pittman, 1992). If students experience positive interactions with special needs students at an early age, their positive childhood memories contribute to a positive perception of persons with disabilities later in life. This helps to prevent the development of stigma as children mature into adulthood.

5.3 Community Interventions

The following recommendations provide opportunities for community members without disabilities to witness the competence of persons with disabilities, while enabling persons with disabilities to form satisfying friendships and increase community involvement in the process.

1. Organize Friendships Between Students with and without Disabilities in Mainstream School Settings (the “Best Buddies” program)

One organization in the United States, Best Buddies, promotes social inclusion through arranged friendships in the school setting

between students with and without disabilities. Each person with disabilities involved in the Best Buddies program is matched with a “buddy” who is similar in age to the person with disabilities but does not have disabilities themselves. Teachers typically match students in a “buddy pair” at the beginning of the school year, taking into account the students’ interests, hobbies, and personalities.

These “buddy pairs” meet at least once a week to spend time together throughout the school year. All persons with and without disabilities participate voluntarily in the Best Buddies program (Best Buddies International, n.d.). We recommend a similar program to Best Buddies which could be implemented by the Ministry of Education and service providers in Albania. We recommend that the Ministry of Education



Figure 5.1: Best Buddies Logo (<https://www.bestbuddies.org/>)

arrange a partnership between mainstream schools and service providers to initiate this inclusion program.

Persons with and without disabilities in elementary, middle, and high school could all take part in this program. The “buddy pairs” would spend time with each other at least once a week after school or during recess. Teachers speak with each “buddy pair” to arrange an appropriate activity for each weekly meeting such as drawing a picture, throwing a ball, or going for a walk. If appropriate, a teacher will remain with both students during their weekly scheduled meeting time. This program encourages persons without disabilities to spend time with students with disabilities. Additionally, students not currently attending mainstream education courses could still be transported to the mainstream school setting after school hours for their “buddy meeting.” This program would also provide persons with disabilities more opportunities to develop friendships with peers outside of the service provider setting.

2. University Students Interning at Service Providers

Some persons with disabilities may be unable to participate in the organized friendship or “Best Buddies” program described above. Our second community

intervention recommendation targets persons with disabilities who have more significant limitations and regularly attend service providers. University students in Tirana may take courses related to persons with disabilities if they are studying education, psychology, or social work. We recommend that universities partner with service providers and send university students to intern with these partners. As part of university coursework requirements, college students could have the opportunity to intern at these service providers and spend time with the service users. Persons without disabilities would interact more with persons with disabilities and college students would gain valuable hands on experience working with persons with disabilities. This recommendation provides benefits for both persons with disabilities attending service providers and university students in Albania. With more staff support from an intern, service providers would have more resources to promote social inclusion within their center.

3. Vocational and Social Skills Trainings for Young Adults with Disabilities at Albanian University Campuses Taught by College Students

Some persons with disabilities may be good candidates for the organized friendship, or “Best Buddies” program, but they may be

older than typical high school students. The organized friendship program is best suited for students in elementary, middle and high school. Young adults with disabilities can face additional challenges to social inclusion once they leave the school setting and have more limited opportunities for community involvement. Our team suggests this third recommendation for persons without severe ID who are between the ages of 16 and 24. Again, we recommend that the mainstream education system and service providers partner with the universities in Albania. We suggest that service providers and public schools allow their service users and students to attend the college campus for vocational and social skills training sessions. These training sessions could be taught by university students studying psychology, social work, or education as part of their coursework related to educating persons with disabilities. An experienced university professor in the field of psychology, social services, or education would oversee these trainings to ensure college students appropriately interact with persons with disabilities.

One high school in the United States piloted a similar program in which high school students with ID or ASD attended a college campus and received trainings taught by university students. In this pilot program, both high school students with disabilities and the university students without disabilities experienced benefits. High school students gained social and vocational skills through the training and college students gained invaluable insights through their firsthand experiences educating persons with disabilities. The high school students participated in a series of vocational trainings in different areas on campus such as the mail room, library, or bookstore (Dolyniuk et al., 2002). While this program involves vocational training, the young adults with and without disabilities also have the opportunity to spend time with one another and get to know each other as peers.

5.4 Conclusion

Few researchers have examined the state of social inclusion for persons with disabilities in Albania. Past Albanian studies rarely document the voices of persons with disabilities themselves, especially persons with intellectual disabilities, developmental disabilities, or neurological disorders such as ASD. Whenever possible, the team listened to the life stories of persons with disabilities from their own perspective. We offered a

platform for these individuals to voice their own concerns regarding their social inclusion in Albania. This research documents the lives of persons with disabilities from all stakeholder's perspectives, however the quotes from the individuals themselves provide critical insights. We encourage researchers to work closely with persons with disabilities in future studies pertaining to social inclusion. This respects the rights of persons with disabilities and counters the misconception that persons with ID and ASD cannot communicate their own thoughts and feelings. Our team observed that persons with disabilities appeared particularly joyful when they were able to speak for themselves during interviews, especially when team members acknowledged that they understood the interviewees' responses.

Discrimination against persons with disabilities persists within Albania and stigma continues to surround disabilities worldwide. We have been honored to assist LNB with their efforts to improve the social inclusion of persons with IDs, developmental disabilities, and ASD in Albania. Humans are animals who have biological instincts of fear towards the unknown (Garpenstrand, Annas, Ekblom, Orelund, & Fredrikson, 2001). While uncertainty and lack of information can lead to stigma and discrimination against persons with disabilities, human behavior can change with time and effort. We hope this research

serves as a steppingstone to reduce the stigma surrounding disabilities over time. Many complicated factors influence the formation of stigma and discrimination towards a population in society. However, with more research comes more documented knowledge. As the public becomes more informed about persons with disabilities, there may be a reduction of the evident stigma and discrimination towards this population across the globe.



Figure 5.2: The Team at UN Albania

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Appendix A: Consent Script for Government Official

Thank you for taking the time to meet with us. We are American students from Worcester Polytechnic Institute working with the Leave No One Behind Program (LNB), a United Nations program led by the United Nations Development Program (UNDP). Our team will be conducting a study within the next seven weeks to investigate the situations of persons with disabilities.

Through this study we hope to learn about the persons' life experiences and assess their inclusion within the community. Our team is interested in interviewing Albanian government officials to learn about the progression of legislation and government services supporting persons with disabilities.

Your participation in this study is voluntary. If you agree to participate you will take part in an interview lasting no more than 45 minutes. **Your identity will be kept confidential.**

Do you consent to Leave No One Behind (LNB) using quotes or audio recordings produced during this interview?

Please clearly mark which of the following that you consent to being used:

☐ Quotes

☐ Audio Recordings

I, _____, consent to the above being used in:

☐ WPI Research Papers

☐ UNDP Documents

☐ UNDP/WPI Video Presentations and Other Media

Signed..... Date.....

Appendix B: Consent Script for Parents of Persons with Disabilities

Thank you for taking the time to meet with us. We are American students from Worcester Polytechnic Institute working with the Leave No One Behind Program (LNB), a United Nations program led by the United Nations Development Program (UNDP). Our team will be conducting a study within the next seven weeks to investigate the situations of persons with disabilities.

Through this study we hope to learn about the persons' life experiences and assess their inclusion within the community. Our team is interested in interviewing parents of persons with disabilities to learn about their perspective on their child's social relationships and inclusion in the community.

Your participation in this study is voluntary. If you agree to participate you will take part in an interview lasting no more than 45 minutes. **Your identity will be kept confidential.**

Do you consent to Leave No One Behind (LNB) using quotes or audio recordings produced during this interview?

Please clearly mark which of the following that you consent to being used:

☐ Quotes

☐ Audio Recordings

I, _____, consent to the above being used in:

☐ UNDP Documents

☐ WPI Research Papers

☐ UNDP/WPI Video Presentations and Other Media

Signed..... Date.....

Appendix C: Consent Script for Service Providers

Thank you for taking the time to meet with us. We are American students from Worcester Polytechnic Institute working with the Leave No One Behind Program (LNB), a United Nations program led by the United Nations Development Program (UNDP). Our team will be conducting a study within the next seven weeks to investigate the situations of persons with disabilities.

Through this study we hope to learn about the persons' life experiences and assess their inclusion within the community. Our team is interested in interviewing service providers assisting persons with disabilities to learn about the services they provide and their perspective on the inclusion of persons with disability in the community.

Your participation in this study is voluntary. If you agree to participate you will take part in an interview lasting no more than 45 minutes. **Your identity will be kept confidential.**

Do you consent to Leave No One Behind (LNB) using quotes or audio recordings produced during this interview?

Please clearly mark which of the following that you consent to being used:

☐ Quotes

☐ Audio Recordings

I, _____, consent to the above being used in:

☐ UNDP Documents

☐ WPI Research Papers

☐ UNDP/WPI Video Presentations and Other Media

Signed..... Date.....

Appendix D: Consent Script without Pictures for Persons with Disabilities

Thank you for taking the time to meet with us. We are American students from Worcester Polytechnic Institute working with the Leave No One Behind Program (LNB), a United Nations program led by the United Nations Development Program (UNDP). Our team will be conducting a study within the next seven weeks to investigate the situations of persons with disabilities.

Our team is interested in interviewing you to learn about your life experiences and how you feel about your inclusion within the community. Your participation in this study is voluntary. If you agree to participate you will take part in an interview lasting no more than 45 minutes. **Your identity will be kept confidential.**

Do you consent to Leave No One Behind (LNB) using quotes, audio recordings, pictures, or drawings produced during this interview?

Please clearly mark which of the following that you consent to being used:

☐ Quotes

☐ Audio Recordings

☐ Photographs

☐ Drawings

I, _____, consent to the above being used in:

☐ UNDP Documents

☐ WPI Research Papers

☐ UNDP/WPI Video Presentations and Other Media

Signed..... Date.....

For parents/guardians/proxies only: If your child is unable to provide consent for themselves, and you would like them to participate in an interview, please determine whether you would like to provide consent for us to use the following:

☐ Quotes

☐ Audio Recordings

☐ Photographs

☐ Drawings

I, _____, as the parent/guardian/proxy of
_____, consent to the above being used in:

☐ UNDP Documents

☐ WPI Research Papers

☐ UNDP/WPI Video Presentations and Other Media

Signed.....

Date.....

Appendix E: Conversation Topics for Interviews with Persons with Disabilities

Introduction	<ul style="list-style-type: none"> Each team member and the translator introduces themselves and says their name to the interviewee. The team explains the following: <ul style="list-style-type: none"> We are students from America doing research on the inclusion of young adults with intellectual disability We would like to speak with you today to learn about your life We would like to talk about what you do during the day and who you spend time with If you feel comfortable, you can talk to us today and share a little bit about yourself Team or proxy introduces consent script before proceeding: <ul style="list-style-type: none"> We will not share this information with your parents You do not have to answer any questions if you do not feel comfortable We will not meet longer than 45 minutes Would you like to speak with us?
Improve the Comfort of the Interviewee	<p>Would you like something to eat or drink?</p> <p>Is sitting or standing more comfortable for you?</p> <p>Is this location good for you?</p> <p>Feel free to tell me if you are uncomfortable.</p> <p>You don't have to answer any questions if you don't feel comfortable.</p>
Casual Introduction	<p>How are you doing?</p> <p>How is your day going?</p>
Interviewee Activities/Interests	<p>What do you like to do for fun?</p> <ul style="list-style-type: none"> Can you tell me a story about a time when you did something fun? <p>Do you like to watch TV?</p> <ul style="list-style-type: none"> What shows? Any movies? <p>Do you have any hobbies?</p> <ul style="list-style-type: none"> Do you participate in sports? <ul style="list-style-type: none"> Which sports?

Interviewee Activities/Interests	<p>What do you like to do for fun?</p> <ul style="list-style-type: none"> Can you tell me a story about a time when you did something fun? <p>Do you like to watch TV?</p> <ul style="list-style-type: none"> What shows? Any movies? <p>Do you have any hobbies?</p> <ul style="list-style-type: none"> Do you participate in sports? <ul style="list-style-type: none"> Which sports? Do you like to do any arts and crafts? <ul style="list-style-type: none"> What kind? Do you listen to music? <ul style="list-style-type: none"> What kind of music do you like? Do you have any pets? <ul style="list-style-type: none"> How do you spend time with your pet? Favorite food and drink? <p>Why do you like ____ ?</p>
Personal Information	<p>When is your birthday?</p> <ul style="list-style-type: none"> How old are you? <p>Where are you from?</p> <p>Where do you live?</p> <ul style="list-style-type: none"> Who do you live with?
Daily Routine	<p>What is your daily routine?</p> <p>What do you do when you wake up?</p> <p>What do you do in the afternoon?</p> <p>What do you do at night?</p> <p>What do you do before bed?</p>

Meal Times	<ul style="list-style-type: none"> • Where do you eat meals? • Who do you eat with? • Have you ever gone out to eat at a restaurant or cafe? <ul style="list-style-type: none"> ○ Do you order for yourself? ○ How do you feel when you order food at restaurants? <ul style="list-style-type: none"> ■ How do you feel about asking for help to order food?
Family	<p>How often are you at home?</p> <p>When do you spend time with family?</p> <p>How do you spend time with your family?</p> <ul style="list-style-type: none"> • Can you tell me a story about when you spent time with family? <p>How do you feel about your family?</p> <ul style="list-style-type: none"> • Does your family help you with anything during the day? <ul style="list-style-type: none"> ○ How do they help you? ○ With reminders? Cooking? Cleaning? ○ How do you feel about your family helping you? <ul style="list-style-type: none"> ■ Would you like to do more things on your own? ■ Would you like more help during the day? ■ Do you feel valued by your family? ○ Do you help your family? <ul style="list-style-type: none"> ■ How so?
Personal Assistant	<p>Do you have a personal assistant?</p> <ul style="list-style-type: none"> • How does your personal assistant help you? <ul style="list-style-type: none"> ○ Cleaning? Reminders? Cooking? Transportation? • Do you like your personal assistant? • Are you satisfied with their help? • How would you like your personal assistant to help you? • Have you ever been dissatisfied with your personal assistant?

Friends	<p>How would you describe a good friend?</p> <ul style="list-style-type: none"> • What is a friend? <p>How often do you spend time with friends?</p> <p>Where do you spend time with friends?</p> <ul style="list-style-type: none"> • Community center? • In the neighborhood? • At home? <p>Do you like spending time with friends?</p> <ul style="list-style-type: none"> • Why or why not? <p>Are you satisfied with your friendships?</p> <ul style="list-style-type: none"> • Why or why not? • Would you like more friends? <p>Can you tell me a story about something you did with a friend?</p> <p>Where do you meet new people?</p> <ul style="list-style-type: none"> • The store? • The park? <p>Have you ever dated?</p> <ul style="list-style-type: none"> • Do you have a romantic partner? • Are you satisfied with your relationship?
Community	<p>What is your neighborhood like?</p> <ul style="list-style-type: none"> • Quiet? Busy? <p>Do you use the car, public bus, bicycle or walk to get to places?</p> <ul style="list-style-type: none"> • Have you ever met any friends on the bus? • Have you ever talked to the bus driver? <p>Do you attend any events in the community?</p> <ul style="list-style-type: none"> • Plays? • Movies? • Arcades? • Concerts? • Carnivals? • Can you tell me about a time when you were in the community? <p>Are you satisfied with your experiences in the community?</p> <ul style="list-style-type: none"> • Why or why not? <p>Do you feel respected by people in the community?</p> <p>Have you ever felt disrespected by people in the community? Do you like Tirana?</p> <ul style="list-style-type: none"> • Why or why not? <p>If you see people you don't know, do you talk to them?</p> <ul style="list-style-type: none"> • Can you tell me about a time you met someone new in the community?

Education	<p>How do feel about your school experiences?</p> <ul style="list-style-type: none"> ● Did/do you like school? ● Do you like learning? ● Did you like your teachers? <p>What kind of activities did/do you take part in at school?</p> <ul style="list-style-type: none"> ● After school? <ul style="list-style-type: none"> ○ With whom? ● Sports? Arts and crafts? <p>Who did/do you sit with at lunch time?</p> <p>What is/was your favorite part of school?</p> <p>Did/do you have friends in school?</p> <p>Do/did you feel that school employees support(ded) you during the day?</p> <ul style="list-style-type: none"> ● Was there a guidance counselor or other teacher who you could go to for help?
Self-Reflection	<p>When do you feel most happy?</p> <p>Where do you feel happy?</p> <ul style="list-style-type: none"> ● At home? ● With friends? ● At school? ● At work? <p>What are your strengths?</p> <p>What do you value most in life?</p> <ul style="list-style-type: none"> ● What makes your life better? <p>Can you tell me a story about a time when you were satisfied/happy?</p> <p>Can you tell me a story about a time when you were not satisfied?</p> <p>What has been difficult for you when:</p> <ul style="list-style-type: none"> ● Traveling in the community? ● Spending time with family members? ● Spending time with friends? <p>How have you handled difficulties during the day?</p> <p>What kinds of support have you received?</p> <ul style="list-style-type: none"> ● What therapies? ● Emotional support? ● Educational support? ● Vocational training? <p>Are you satisfied with the support you receive?</p>

Dreams for the Future	<p>Do you have any wishes or dreams for the future? Can you tell me about them?</p> <ul style="list-style-type: none"> ● Dream job? ● Do you want to start a business? ● Do you want to have a family? ● Get married? Travel around the world? ● Do you want any pets? ● Would you like to spend more time with people? <ul style="list-style-type: none"> ○ Friends? ○ Family? <p>Do you feel like you have the opportunities to achieve your dreams?</p> <ul style="list-style-type: none"> ● The connections with people for a potential career? ● How do family/friends support you in achieving your dreams? ● How does therapy or services help you reach your dreams?
Optional Drawing/Sculpting Activity	<p>Example prompts:</p> <ul style="list-style-type: none"> ● Can you draw your neighborhood? ● Can you draw who you spend time with during the day? Family? Friends? ● What makes your life better? Can you draw/sculpt this?
Optional Photo-Elicitation	<p>For first interview anticipating second interview:</p> <ul style="list-style-type: none"> ● By the next interview, can you take a couple of photos of things that interest you or that you want to share with us? ● Use smartphone or camera if available ● As many photos as you want <p>For second interview if interviewee has already taken photos:</p> <ul style="list-style-type: none"> ● Why did you choose this photo? ● What stood out to you that made you take this picture? ● What is your favorite thing about this photo? ● What does this photo represent for you? ● Does this photo remind you of anything? ● How does this photo make you feel? ● Happy? Sad? Fulfilled? Nervous?

Appendix F: Conversation Topics for Interviews with Parents of Persons with Disabilities

Introduction	<ul style="list-style-type: none"> Each team member and the translator introduces themselves and says their name to the interviewee. The team explains the following: <ul style="list-style-type: none"> We are students from America doing research on the inclusion of young adults with intellectual disability We would like to speak with you today to learn about your child and the relationship you have with them Team explains consent script before proceeding: <ul style="list-style-type: none"> We will not share this information with your child You do not have to answer any questions if you do not feel comfortable We will not meet longer than 45 minutes Would you like to speak with us? 	Interactions with Peers	<p>Who does [child's name] spend time with?</p> <ul style="list-style-type: none"> Does [child's name] have friends? <ul style="list-style-type: none"> How does [child's name] view friendship? How often does [child's name] interact with friends? Where does [child's name] spend time with peers? Does [child's name] have a romantic partner? How does [child's name] feel about their friendships? <ul style="list-style-type: none"> Would [child's name] like more relationships? Do you think [child's name] is satisfied with their friends? Can you tell me about a time when [child's name] interacted with their peers?
Improve the Comfort of the Interviewee	<p>Would you like something to eat or drink?</p> <p>Is sitting or standing more comfortable for you?</p> <p>Is this location good for you?</p> <p>Feel free to stop me if you are uncomfortable.</p> <p>You don't have to answer any questions if you don't feel comfortable.</p>	Community Involvement	<ul style="list-style-type: none"> How does [child's name] spend time in the community? How often does [child's name] interact with other community members? Do you think [child's name] is satisfied with their community involvement?
General Information	<p>What is your child's name?</p> <p>How old is [child's name]?</p> <p>Where does [child's name] live?</p> <ul style="list-style-type: none"> Who does [child's name] live with? <p>What is [child's name]'s disability?</p> <ul style="list-style-type: none"> Severity? 	Child's Education	<p>Has [child's name] attended school?</p> <ul style="list-style-type: none"> How would you describe [child's name]'s school experience? <ul style="list-style-type: none"> Public school or development center? Did [child's name] have friends? Has [child's name] ever expressed any dissatisfaction with their education? Do you think [child's name] enjoyed school? How would you describe [child's name]'s interactions with other students and teachers? <ul style="list-style-type: none"> Did [child's name] get along with other students? Was [child's name] satisfied with their relationships with other students and teachers?
Daily Routine	<p>What does [child's name] do throughout the day?</p> <ul style="list-style-type: none"> Employed? Attend therapies? Stay at home? 	Relationship with Child	<p>What do you love about [child's name]?</p> <p>Can you tell me a story about when you and [child's name] spent quality time together?</p>

Child's Desires and Feelings	<p>Can you tell me about a time when [child's name] was proud of their accomplishments?</p> <p>What does [child's name] value in life?</p> <ul style="list-style-type: none"> • How does [child's name] choose to spend their time? <p>How does [child's name] view their own strengths and weaknesses?</p> <p>Has [child's name] ever expressed wishes for their future?</p> <ul style="list-style-type: none"> • Desire to work? • Desire to start a family? • Desire to be independent? <p>Has [child's name] ever told you about anything they are unhappy about?</p> <p>What makes [child's name] happy? Satisfied?</p> <ul style="list-style-type: none"> • Where and when does [child's name] feel most satisfied?
Parent's Desires for their Child	<p>What goals do you have for [child's name]?</p> <p>Would you like [child's name] to spend more time with other people?</p> <p>Would you like [child's name] to be more independent?</p> <ul style="list-style-type: none"> • How would you feel about [child's name] dating? • Can you envision [child's name] starting a family of their own? • How would you feel about [child's name] starting their own family? • Would you like [child's name] to live on their own? In a development center? With family members? • Would you like [child's name] to spend more time in the community? <ul style="list-style-type: none"> ○ Attend more community events? ○ Participate in volunteer experiences or work at a business?

Support for their Child	<p>How do you help [child's name] throughout the course of the day?</p> <ul style="list-style-type: none"> • With what tasks? <ul style="list-style-type: none"> ○ Cooking, cleaning, reminders, etc.
Programs/Services	<p>What community services have you and [child's name] used?</p> <ul style="list-style-type: none"> • Therapies? • Vocational training? <p>Has [child's name] ever told you about their experiences with therapies/services?</p> <ul style="list-style-type: none"> • Are they satisfied with the support? • Has [child's name] ever asked for more therapies/services? • Has [child's name] ever expressed dissatisfaction with the services they receive? <p>Does [child's name] receive disability benefits?</p> <p>Has [child's name] attended a development center?</p> <p>Have you reached out to the municipal government for any assistance?</p> <p>What type of local services do you think [child's name] could benefit from?</p>

Appendix G: Conversation Topics for Interviews with Service Providers

Introduction	<ul style="list-style-type: none"> Each team member and the translator introduces themselves and says their name to the interviewee. The team explains the following: <ul style="list-style-type: none"> We are students from America doing research on the inclusion of young adults with intellectual disability We would like to speak with you today to learn about: <ul style="list-style-type: none"> Your organization How your services impact the inclusion of young adults with ID Any personal experiences you may have when observing young adults with ID and their families Team explains consent script before proceeding: <ul style="list-style-type: none"> This information will remain confidential You do not have to answer any questions if you do not feel comfortable We will not meet longer than 45 minutes Would you like to speak with us? 	How does your organization promote social inclusion?	<p>Does your organization assist young adults in becoming more included within the community?</p> <ul style="list-style-type: none"> If yes, how so? Do any of your services include a community-based component such as volunteering or vocational training at local businesses? <p>Does your organization encourage interactions between persons with intellectual disability and their peers?</p> <ul style="list-style-type: none"> If yes, how so? <p>Do any of your services support young adults with ID in developing social or communication skills?</p> <ul style="list-style-type: none"> If yes, how so?
Tell us about your organization	<p>What does your organization do?</p> <p>What is the history of your organization?</p> <p>Does your organization use the person-centered planning approach?</p>	Tell us about your opinions on young adults with intellectual disabilities	<p>Relationships with People:</p> <p>Do most young adults in your programs have many friends?</p> <p>Who would you say young adults with ID spend the most time with?</p> <ul style="list-style-type: none"> Family? Friends? Service providers? <p>Do you think your service users desire more relationships with people?</p>
Tell us about your services	<p>What services, if any, do you provide to adults with ID aged 21-30?</p> <p>How are your services funded?</p> <p>What are some services you would like to see added to your program?</p> <ul style="list-style-type: none"> What would be the aim of these services? Would any of these services aim to assist the inclusion of young adults with ID in their communities? What limitations, if any, does your organization face when providing services? <p>How do you take into account the desires of young adults with ID when providing services?</p>		<p>Involvement in Community:</p> <p>Where would you say persons with disabilities spend most of their time?</p> <ul style="list-style-type: none"> At home? In the community? In a development center? <p>In your opinion, do you feel young adults with ID are isolated?</p> <p>Do you think service users would like to spend more time in the community?</p>

<p>Tell us about the role of family members in your services</p>	<p>How involved are family members in your services? What have you observed when parents interact with their children with intellectual disability?</p> <ul style="list-style-type: none"> ● Has a parent ever disagreed with their child when considering the most beneficial therapies/services? ● How has your organization handled disagreements between parents and their children? ● What happens when a child desires one thing but the parents prefer different therapies for their child? ● Have any young adults with ID told you about their wishes for their future? <ul style="list-style-type: none"> ○ Does your organization support their desires? ○ Are their parents supportive of their child's desires?
<p>Role of Government</p>	<p>Does your organization receive any support from the government? Can you tell us about how the government impacts the inclusion of young adults with ID?</p>
<p>Follow-up</p>	<p>Do you have any service users we could have an interview with? If possible, we would also like to interview their parents separately.</p>

Appendix H: Conversation Topics for Interviews with Government Officials

Introduction	<p>Each team member and the translator introduces themselves and says their name to the interviewee. The team explains the following:</p> <ul style="list-style-type: none"> ○ We are students from America doing research on the inclusion of young adults with intellectual disability ○ We would like to speak with you today to learn about: <ul style="list-style-type: none"> ■ The role of the Albanian government in supporting persons with disabilities ■ The Albanian policies in place which promote social inclusion for persons with intellectual disability ○ Team explains consent script before proceeding: <ul style="list-style-type: none"> ■ We will not disclose your identity or name in any documents ■ You do not have to answer any questions if you do not feel comfortable ■ We will not meet longer than 45 minutes ■ Would you like to speak with us?
Interviewee's Role in the Government	<p>Can you tell me about your role in the government?</p> <ul style="list-style-type: none"> ● What is your position? ● What are you most passionate about? ● Why did you choose to run for this role? <p>Do you work under a specific section or ministry of the government?</p> <ul style="list-style-type: none"> ● Can you tell me about the role of the specific ministry/department you are a part of? ● What tasks does your department complete on a daily basis? <ul style="list-style-type: none"> ○ Writing new policies? <ul style="list-style-type: none"> ■ What area does your department's policies focus on? ○ Updating legislation? ○ Public speaking? <p>Has any of your work or your department's work pertained to persons with disabilities?</p> <ul style="list-style-type: none"> ● Have you worked on any legislation pertaining to persons with ID? ● Can you tell me about any interactions you have had with persons with ID?

Policies for Persons with ID	<p>What is your main priority when creating and revising legislation which supports the rights of persons with intellectual disability?</p> <ul style="list-style-type: none"> ● Voting rights? ● Employment? ● Independent decision making? ● Independent living? ● Social Inclusion? <p>How have policies involving social inclusion developed in the last decade?</p> <ul style="list-style-type: none"> ● Have the policies improved? If yes, how so? ● What policies do you think have the biggest impact on improving inclusion for these young adults with ID? ● What successes have come out of newly created policies? <ul style="list-style-type: none"> ○ Why do you think these policies led to success? ● Which policies have been less successful? <ul style="list-style-type: none"> ○ Why do you think these policies have not yielded as much success?
Role of NGOs/Service Providers	<p>What role do you believe NGOs and service providers play in improving the inclusion of young adults with ID into their community?</p> <ul style="list-style-type: none"> ● What do you think services should focus more on? ● How can they improve their role in helping foster inclusion? ● How does the government interact with service providers who assist persons with ID? <ul style="list-style-type: none"> ○ Is there any partnership between the government and service providers?
Role of Families	<p>What role do you believe parents play in helping their children with ID become more included in the community?</p> <p>How do you believe families could improve the social inclusion of their child?</p> <ul style="list-style-type: none"> ● What should they prioritize? ● What government supports are offered to parents who have a child with ID ?

Role of Schools	<p>What role do you believe schools play in the inclusion of persons with intellectual disabilities?</p> <ul style="list-style-type: none"> • Do you believe schools are accessible for persons with disabilities? • How do you think schools are doing with implementing new inclusion and accessibility laws? • How are students with disabilities included by their peers and teachers in schools? <ul style="list-style-type: none"> ○ Do you feel students with disabilities face a stigma in schools?
Plans for the Future	<p>Once the term of the National Action plan concludes in 2021 are there any plans for the continuation of its measures?</p> <ul style="list-style-type: none"> • Are there any plans for new policies? • What are your department's priorities for helping persons with disabilities in the future?
Discrimination	<p>Are any policies focused on addressing discrimination towards persons with disabilities?</p> <ul style="list-style-type: none"> • Do you believe persons with disabilities are stigmatized in Albania society? • Are there policies or plans in place to promote the self-advocacy of persons with disabilities?

Appendix I: Detailed Sub-Research Questions

- How are persons with disabilities involved within their community?
 - What community events and activities do they take part in?
 - What community services and supports do they receive?
 - Are they employed? What career opportunities have they experienced?
 - How do they navigate the community?
 - Do they feel free to make choices in their daily lives?
 - How do service providers promote the inclusion of persons with ID in the community?
- How do persons with disabilities interact with their peers?
 - Who do they spend time with during the week?
 - Do they feel respected by peers?
 - Do they have romantic relationships?
 - Do they feel isolated?
 - How do Albanian service providers promote the interactions between persons with ID and their peers?
- How do persons with disabilities interact with their families?
 - What support do parents provide their children with intellectual disabilities?
 - How do parents influence decisions of their children with intellectual disability?
 - Would young adults with intellectual disability like more autonomy within their family?
 - How do parents affect the social inclusion of their child?
- How do persons with disabilities reflect on their lives?
 - What do they value?
 - What do they feel is most important in their lives?
 - Are they satisfied with their social relationships and current community involvement?
 - What are their dreams for the future?
 - Would they like to live with their parents?
 - Would they like to be more independent?
 - Would they like to live alone?
 - What career would they like?
 - Are their goals and wishes feasible with the current support available?